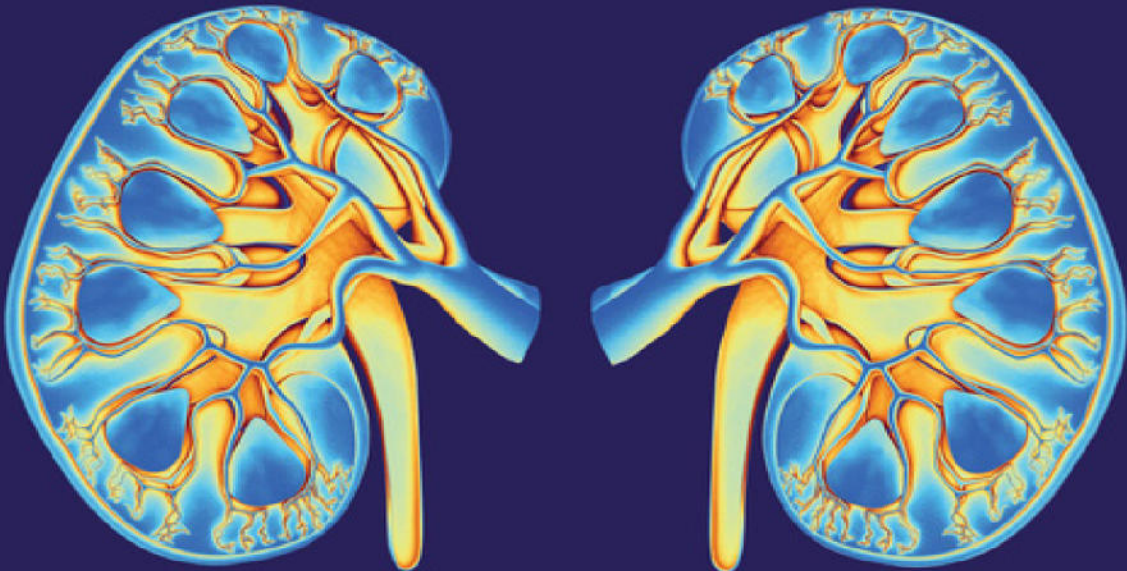


SIXTH EDITION

RENAL NURSING

CARE AND MANAGEMENT OF
PEOPLE WITH KIDNEY DISEASE



EDITED BY
NICOLA THOMAS AND HELEN NOBLE

WILEY Blackwell

Renal Nursing

SIXTH
EDITION

Renal Nursing

Care and Management of People
with Kidney Disease

Edited by

Nicola Thomas

London South Bank University, London, UK

Helen Noble

Queen's University Belfast, Belfast, UK

WILEY Blackwell

This edition first published 2024
© 2024 John Wiley & Sons Ltd

Edition History

[5e, 2019 by Wiley-Blackwell]

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, except as permitted by law. Advice on how to obtain permission to reuse material from this title is available at <http://www.wiley.com/go/permissions>.

The right of Nicola Thomas and Helen Noble to be identified as the authors of the editorial material in this work has been asserted in accordance with law.

Registered Office(s)

John Wiley & Sons, Inc., 111 River Street, Hoboken, NJ 07030, USA

John Wiley & Sons Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

For details of our global editorial offices, customer services, and more information about Wiley products visit us at www.wiley.com.

Wiley also publishes its books in a variety of electronic formats and by print-on-demand. Some content that appears in standard print versions of this book may not be available in other formats.

Trademarks: Wiley and the Wiley logo are trademarks or registered trademarks of John Wiley & Sons, Inc. and/or its affiliates in the United States and other countries and may not be used without written permission. All other trademarks are the property of their respective owners. John Wiley & Sons, Inc. is not associated with any product or vendor mentioned in this book.

Limit of Liability/Disclaimer of Warranty

The contents of this work are intended to further general scientific research, understanding, and discussion only and are not intended and should not be relied upon as recommending or promoting scientific method, diagnosis, or treatment by physicians for any particular patient. In view of ongoing research, equipment modifications, changes in governmental regulations, and the constant flow of information relating to the use of medicines, equipment, and devices, the reader is urged to review and evaluate the information provided in the package insert or instructions for each medicine, equipment, or device for, among other things, any changes in the instructions or indication of usage and for added warnings and precautions. While the publisher and authors have used their best efforts in preparing this work, they make no representations or warranties with respect to the accuracy or completeness of the contents of this work and specifically disclaim all warranties, including without limitation any implied warranties of merchantability or fitness for a particular purpose. No warranty may be created or extended by sales representatives, written sales materials or promotional statements for this work. This work is sold with the understanding that the publisher is not engaged in rendering professional services. The advice and strategies contained herein may not be suitable for your situation. You should consult with a specialist where appropriate. The fact that an organization, website, or product is referred to in this work as a citation and/or potential source of further information does not mean that the publisher and authors endorse the information or services the organization, website, or product may provide or recommendations it may make. Further, readers should be aware that websites listed in this work may have changed or disappeared between when this work was written and when it is read. Neither the publisher nor authors shall be liable for any loss of profit or any other commercial damages, including but not limited to special, incidental, consequential, or other damages.

Library of Congress Cataloging-in-Publication Data Applied for:

Paperback: 9781394178766

Cover Design: Wiley

Cover Image: © ALFRED PASIEKA/SCIENCE PHOTO LIBRARY/Getty Images

Set in 9.5/12pt STIXTwoText by Straive, Pondicherry, India

Contents

List of Contributors	vii
Foreword	viii
Preface	ix
Acknowledgements	x

1	The History of Kidney Dialysis and Transplantation	1

Nicola Thomas

2	Applied Anatomy and Physiology, the Kidney Disease Process, and Kidney Investigations	14

Claire Carswell and Stephen O'Neil

3	Patient and Carer Involvement in Kidney Care, Education, and Research	52

Brian Gracey, Linda Gracey, Fiona Loud, and Nicola Thomas

4	Emotional Well-being	67

Fiona Murphy

5	Acute Kidney Injury	115

Marissa Dainton

6	Chronic Kidney Disease and Advanced Kidney Care	132

Nicola Thomas and Catherine Maina

7	Haemodialysis	148

Catherine Fielding

8	Peritoneal Dialysis	189
	<i>Sally Punzalan</i>	
9	Kidney Transplantation	220
	<i>Victoria Dunsmore</i>	
10	Non-dialytic Options and a Palliative Conservative Kidney Management Approach	262
	<i>Helen Noble, Claire Carswell, and Ian Walsh</i>	
11	Kidney Care in Infancy, Childhood, and Early Adulthood	274
	<i>Diane Blyton and Shelley Jepson</i>	
12	Nutrition in Kidney Disease	288
	<i>Barbara Engel and Pearl Pugh</i>	
13	Quality Improvement and Nursing Research in Kidney Care	326
	<i>Nicola Thomas</i>	
	Index	334

List of Contributors

Diane Blyton

Nottingham Children's Hospital, Nottingham, UK

Claire Carswell

Queen's University Belfast, Belfast, UK

Marissa Dainton

Canterbury Christ Church University, Canterbury, UK

Victoria Dunsmore

Barts Health NHS Trust, London, UK

Barbara Engel

University of Surrey, Guildford, UK

Catherine Fielding

University Hospitals of Derby and Burton NHS Foundation Trust, Derby, UK

Brian Gracey

Linda Gracey

Shelley Jepson

Nottingham Children's Hospital, Nottingham, UK

Fiona Loud

Kidney Care UK, Alton, UK

Catherine Maina

St Georges University Hospitals NHS Foundation Trust, UK

Fiona Murphy

Trinity College Dublin, Dublin, Ireland

Helen Noble

Queen's University Belfast, Belfast, UK

Stephen O'Neil

Queen's University Belfast, Belfast, UK

Pearl Pugh

University of Nottingham, Nottingham, UK

Sally Punzalan

Imperial College Healthcare NHS Trust, UK

Nicola Thomas

London South Bank University, London, UK

Ian Walsh

Queen's University Belfast, Belfast, UK

Chronic kidney disease is a global health burden and has become a major public health issue, as it is common, harmful, often treatable and preventable. Although progress has been made in identifying chronic kidney disease earlier and delaying the need for dialysis and transplantation, the number of people affected by kidney disease continues to grow each year. Over 2 million people worldwide currently receive treatment with dialysis or a kidney transplant to stay alive, yet this number may only represent 10% of people who actually need the treatment to live.

Acute kidney injury (AKI) accounts for 8–16% of hospital admissions, with >1% of health service expenditure being attributed to AKI in the UK. The International Society of Nephrology has an ambitious aim to prevent all avoidable deaths from AKI worldwide by 2025. Nurses play a key role in the early recognition and treatment of AKI, and nurses working in kidney care are no exception. They have a crucial role in adding quality to care.

People with chronic kidney disease have a wide range of physical and emotional needs. These include encouragement to achieve behavioural change goals they have set themselves, support with decision-making, education about their condition, traditional basic care needs individually delivered with compassion, and an understanding of the complexity of kidney disease along with other co-morbidities. The skills and competencies required to address these needs are the foundation of high-quality care delivered by both registered and non-registered nurses. Caring for people with kidney disease is a ‘hands-on’ job requiring an understanding of psychology – the person, the carers and the families, and your own; knowledge of the biology and pathophysiology of the kidney; expertise in the nursing of the acutely unwell, and the management

of complex long-term conditions; as well as emotional resilience. Kidney care nurses recognise the people they care for have a common disease, but each individual’s experience is unique, requiring support and encouragement appropriate to their age, cultural background, and degree of health literacy. As such, nurses specialising in kidney care are pivotal to the multi-professional team. Not only do they bring their understanding of kidney disease and experience of managing others in a similar situation, they also are the advocate for holistic care and act as a catalyst for shared decision-making.

To achieve such high standard of care, the appropriate education and training is needed to develop this vast knowledge base and practical skills. Nurses access specialist knowledge in a variety of formats, either e-learning, textbooks such as this, or even social media. Since the dissolution of national renal courses, there is a lack of educational standardisation, which the Association of Renal Nurses UK (ANN UK) has begun to address with the launch of an online renal course designed for registered nurses with at least 6 months’ experience in kidney care. This is the first step towards developing a national educational framework for kidney care nurses. As part of this educational framework, the 6th edition of *Renal Nursing* will provide you with the information you need to understand the fundamentals of kidney care. Use this textbook in conjunction with gaining practical hands-on experience in dialysis units, inpatient wards, outpatient settings, and home therapies and you will have the knowledge and skills to make a vast difference to many people with kidney disease.

Karen Jenkins President of the Association of
Nephrology Nurses, UK

Preface

We have very much enjoyed editing the sixth edition of this successful book for nurses and allied health-care professionals working in nephrology, dialysis, and transplantation, along with expert colleagues. The past 5 years have again seen tremendous changes in kidney care in the UK, particularly improvements in patient experience, such as developments in peer support programmes and renal arts. Chapter 3 of this textbook is always warmly received, as it provides a patient and carer perspective on care and encourages us to think in the 'patient's shoes'.

This book is generally for those who are new to kidney care. Nurses who are studying on preregistration courses and practitioners who are commencing a post-registration course in renal nursing will find it particularly helpful. It also serves as an excellent foundation for nurses wishing to refresh their knowledge about an area of kidney care in which they are currently not practising, or for other members of the multi-professional team. This new edition is again written in a style that promotes kidney care for what it is: a dynamic, varied, and rewarding specialty.

Each chapter has been written by an expert in their field. Kidney nurses in the twenty-first century face a

constant challenge to keep abreast of developments in care and management. What does not change is the constant physical and psychosocial challenges that patients and their families have to face. This must always be in our minds. During our long careers in renal nursing, we have heard the repeated request from patients that we emphasise what *can* be done rather than what cannot. The word *restriction* should not be part of a kidney nurse's vocabulary: Why not fluid or dietary *allowance*? As in the fifth edition, we have endeavoured to use language in this book which puts patients at the centre of care.

We are delighted that the Association of Nephrology Nurses, UK (ANN-UK), launched in 2018, is going from strength to strength and aims to reintroduce a framework for renal nursing education in the UK. We hope that this latest edition complements that vision and will continue to encourage kidney nurses to care for their patients with compassion, sensitivity, and understanding.

*Professor Nicola Thomas
(London) and Professor Helen Noble (Belfast)
March 2024*

Acknowledgements

Recognition must go to those authors who wrote chapters for the previous edition. They are Charlotte Chalmers, Ratna Das, Althea Mahon, Shahid Nazir Muhammad, and Linsey Worsey.

The History of Kidney Dialysis and Transplantation

CHAPTER 1

Nicola Thomas

London South Bank University, London, UK

LEARNING OUTCOMES

- to understand the evolution of haemodialysis (HD), peritoneal dialysis (PD), and transplantation.
- to appreciate the challenges that healthcare professionals working in kidney care have had to overcome.
- to evaluate the changing focus of kidney care in the twenty-first century.
- to identify the opportunities for nurses working in kidney care in the future.

INTRODUCTION

The introduction of dialysis as a life-saving treatment for end-stage kidney disease (ESKD) was not the result of any large-scale research programme; rather, it emerged from the activities of a few pioneering individuals who were able to use ideas, materials, and methods from a range of developing technologies.

Haemodialysis (HD), as a routine treatment for ESKD, was initiated in the 1960s, followed by continuous ambulatory peritoneal dialysis (CAPD) in the late 1970s. The recognition of the need for immunosuppression in transplantation in the 1960s enabled it to become the preferred treatment for many patients.

HAEMODIALYSIS

THE BEGINNING

It was the Romans who first used a form of dialysis therapy by giving hot baths to patients to remove urea. The action of the hot water made the patient sweat profusely and this, together with the toxins diffusing through the skin into the bath water, would temporarily relieve symptoms. However, the Romans did not understand why the treatment worked. The effect was to leave the patient

fatigued but, as the only hope, this treatment was still used on occasion into the 1950s.

The first time that the term *dialysis* was used was in 1854, by Thomas Graham, a Scottish chemist (Graham 1854). He used *dialysis* to describe the transport of solutes through an ox bladder, and this was the catalyst for other researchers working in a similar field to focus on the membrane.

Membranes were made from a variety of substances, including parchment and collodion (Eggerth 1921). Collodion is a syrupy liquid that dries to form a porous film and allows the passage of small-molecular-weight substances, whilst being impermeable to substances with a molecular weight greater than 5 kDa. In 1889, B.W. Richardson referred to the use of collodion membranes in the dialysis of blood. So, by this method, living animals were dialysed in experimental conditions (Richardson 1889), but the limiting factor that prevented the treatment being used in humans at this time was the lack of suitable materials.

PRE-1920

It was not until 1913 that the first article on the technique of HD, named the *artificial kidney*, was reported. Experimental dialysis was performed on animals by using variances in the composition of dialysis fluid (Abel et al. 1914). Substances could be added to the solution to avoid their net

removal. The main aim of the experiments was the removal of salicylates. The removal of fluid and toxins accumulated due to kidney disease was not, at this time, considered.

In 1914, Hess and McGuigan were experimenting with dialysis in a pharmacology laboratory in Chicago. As a result, they were able to transfer sugar from tissue to blood and from the blood across a collodion membrane. The design of the dialyser minimised the length of blood tubing from the patient, and a high blood flow was achieved by connection to the carotid artery in an effort to minimise the necessity to use an anticoagulant. A single U-shaped collodion tube was inserted into a glass cylinder with a rubber stopper at one end. The blood flow both to and from the dialyser was at one end, with a port for adjusting the pressure inside the tube. These experiments were only performed on animals. The only anticoagulant available was in the form of an extract obtained from crushed leech heads, called hirudin. This was far from satisfactory, even though leeches were plentiful and readily available from the corner shop for around \$25 per thousand.

THE 1920s

The first dialysis performed on a human was carried out by German physician Georg Haas in Giessen in the latter half of the 1920s. He performed six dialysis sessions in six patients. Handmade collodion membranes were used, and clotting was prevented by using hirudin and, later, a crude form of heparin. Haas used multiple dialysers concurrently to increase the surface area of blood exposed to the dialysis fluid. The six dialysers were arranged in parallel and he found that the arterial pressure of the blood was insufficient to propel the blood through the entire extracorporeal circuit. He therefore introduced a pump into the circuit. Haas received little support from his hospital and his colleagues, so by the late 1920s he gave up and the work was stopped. Haas died in 1971 at the age of 85 years, and he was honoured as the pioneer of dialysis.

Despite these treatments, carried out from the 1920s to the 1940s, those individuals with uraemia suffering from poor appetite and vomiting could be offered nothing more than bed rest and a bland salt-free diet composed mainly of vegetables, carbohydrate, and fat to reduce protein metabolism. Dialysis was not considered a realistic option, and the conservative therapy was only offered as a palliative measure.

In 1923, Heinrich Necheles became the founder of the contemporary dialyser. He experimented with the sandwiching of membranes, thus giving an increased surface area without the necessity for multiple dialysers. The membrane used was the peritoneum of a sheep. As this

membrane was prone to expansion, support sheets were placed between the layers of membrane, thus allowing a large surface area of membrane to come into contact with the dialysis fluid. Other features introduced by Necheles were a heater, the priming of the pathway for the blood, and a filter to prevent clots returning to the patient.

THE 1930s

The 1930s saw great advances in synthetic polymer chemistry, resulting in the availability of cellulose acetate, which could be used as a membrane for HD. It was in 1937 that the first synthetic membrane was used by the American scientist William Thalhimer. The material, cellophane (a form of cellulose acetate), was used extensively in the sausage industry, and had the potential that was not recognised for some years. In the mid-1930s came the purification of heparin (Thalhimer et al. 1938), which could be used as an anticoagulant. Together, these two advances gave rise to the next stage of development, which took place in 1943.

THE 1940s AND 1950s

Willem Kolff, a physician working in Groningen in Nazi-occupied Holland, had his attention drawn to the work of a colleague who was concentrating plasma by using cellulose acetate as a membrane and immersing it in a weak solution of sugar. Kolff noticed that toxins in the blood were altered by this method (Kolff 1950). He built a rotating drum dialyser, which provided sufficient surface area for his first attempt at human dialysis (Kolff and Berk 1944). His machine consisted of 30 m of cellophane tube that was wound round a large cylinder. The cylinder was placed in a tank containing a weak solution of salts (the dialysate). The patient's blood was passed through the cellophane tube, the walls acting as a semipermeable membrane. Blood flow was achieved by the addition of a circuit containing a burette, which, when filled with blood, could be raised high enough to allow the blood to flow into the dialyser. The burette was then lowered, allowing the blood to drain back, and raised again to allow the blood to return to the patient. The slats in the construction of the cylinder were made of wood due to the shortage at this time of materials such as aluminium. Six hours were required for the treatment, and the efficiency of dialysis was reasonable (170 ml min^{-1} urea). Fluid could only be removed by increasing the osmotic pressure of the dialysate fluid by the addition of sugar, as an increase in pressure on the membrane would result in rupture (Kolff 1965).

The whole procedure was very time consuming and labour intensive, as the process required attention at all times to raise and lower the burette and observe the

membrane for rupture, which happened frequently. Repairs to the membrane were carried out by inserting a glass tube at the point of rupture.

Kolff's first clinical experience was gained with a 29-year-old woman with chronic nephritis. Her blood urea was kept stable for 26 days, but after 12 sessions of dialysis, her blood urea began to increase and she subsequently died.

After the war, in 1945, Kolff's technique was widely used, particularly in Sweden and the United States. The treatment was initially for acute kidney injury, when kidney function could be expected to return to normal following a short period of dialysis treatment. It was widely used in the Korean war in 1952 to treat trauma-induced acute kidney injury. This team, led by Paul Teschan, was trained to use the rotating drum dialyser and saved many lives by lowering the high potassium levels of those injured (Teschan 1955).

Some of the earliest research carried out on fluid removal from the blood using negative pressure was conducted by M.R. Malinow and W. Korzon at Michael Reese Hospital in Chicago in 1946 (Malinow and Korzon 1947). The device used was the earliest version of a dialyser with multiple blood paths and negative pressure capacity. It had parallel sections of cellulose acetate tubing and, by adding layers of tubing, the surface area of the device could be increased. The diffusion properties of this device were not considered, as it was intended only for removal of water from the blood. The device required a low priming volume and the circuit included a blood pump.

In the 1940s, interest in dialysis as a treatment for ESKD had spread throughout Europe and across to Canada as the need for dialysis was becoming widely recognized. After obtaining drawings of the Kolff dialyser, Russell Palmer and a colleague from Vancouver, in Canada, built a replica and dialysed their first patients in September 1947 (Palmer and Rutherford 1949).

Kolff was invited to take his artificial kidney to New York, where he trained physicians in the operation of the life-saving device. There was resistance from hospital staff at Mount Sinai Hospital, who only permitted the treatment to be administered in the surgical suite after normal surgical schedules were completed for the day. The first successful dialysis in Mount Sinai Hospital was in January 1948, in a female admitted to hospital having inserted mercury tablets into her vagina to induce an abortion (Fishman et al. 1948). Eight hours after the first dialysis using the Kolff machine, the patient passed urine and the dialysis was deemed a success. People with drug overdose were then regularly treated by use of the rotating drum dialyser until 1950.

To expand the use, the rotating drum needed to be modified to make it easier to use. Kolff enlisted the help of Dr. Carl Walter, who worked at the Peter Brent



FIGURE 1.1 Artificial kidney machine (Kolff-Brigham), France, 1955. *Source:* With kind permission from Science and Society Picture Library.

Brigham Hospital. Together with Edward Olson, an associate engineer from Fenwal, they set about designing and building a new version of the Kolff drum. Stainless steel was used for the drum, and refinements included a hose for filling the pan with 100 l of dialysate fluid, which was heated, and a hood to cover the drum. A tensioning device was used on the cellophane membrane as it had a tendency to stretch during use. The split connection for the patient's tubing was introduced, and this allowed the patient's tubing to remain stationary whilst the drum rotated. This was made leakproof, and a Lucite hood was added to overcome heat loss from the extracorporeal blood (Figure 1.1). These improvements paved the way for wider acceptance of the use of dialysis treatment (Merrill et al. 1950).

When the Kolff-Brigham kidney was used, the heparin dose ranged from 6000 to 9000 units, and was infused prior to the start of the treatment. The dialyser was primed with blood, and the blood flow to the dialyser was limited to 200 ml at a time to prevent hypotension. To assist blood flow, a pump was inserted in the venous circuit rather than the arterial side, to minimise the probability of pressure buildup in the membrane, which would cause a rupture.

This version of the Kolff-Brigham dialysis machine was used from 1948; in all, over 40 machines were built and exported all over the world.

THE 1950s

The Allis-Chalmers Corporation was one of the first companies to produce dialysis machines commercially. They were prompted into manufacture when an employee

developed ESKD. There was no Kolff machine available and so the firm turned its attention to producing their version of the Kolff rotating drum. The resulting machine was commercially available for \$5600 and Allis-Chalmers produced 14 of these machines and sold them all over the United States into the early 1950s.

In October 1956, the Kolff system became commercially available, so the unavailability of equipment could no longer be used as an excuse for non-treatment of patients. Centres purchased the complete delivery system for around \$1200 and the disposables necessary for the treatment were around \$60. The system was still mainly used for reversible acute kidney injury caused by drug overdose.

DEVELOPMENT OF THE DIALYSER FROM 1950s ONWARDS

Jack Leonards and Leonard Skeggs produced a plate dialyser, which would permit a reduction in the priming volume and allow negative pressure to be used to remove fluid from the patient's system (Skeggs et al. 1949). A modification to this design included a manifold system, which allowed variation of the surface area without altering the blood distribution. Larger dialysers followed, which necessitated the introduction of a blood pump.

In the late 1950s, Fredrik Kiil of Norway developed a parallel plate dialyser, with a large surface area (1 m^2), requiring a lower priming volume. A new cellulose membrane, Cuprophane, was used, and this allowed the passage of larger molecules than other materials that were available at that time. The Kiil dialyser could be used without a pump. Kiil dialysed the patients using their own arterial pressure. This dialyser was widely used because the disposables were relatively inexpensive when compared with other dialysers available at that time.

A crude version of the capillary-flow dialyser, the parallel dialyser, was developed, using a new blood pump with a more advanced version of the Alwall kidney (MacNeill 1949). However, it was John Guarino who incorporated the important feature of a closed system, a visible blood pathway.

To reduce the size of the dialyser without reducing the surface area, William Y. Inouye and Joseph Engelberg produced a plastic mesh sleeve to protect the membrane. This reduced the risk of the dialysis fluid coming into contact with the blood. This was a closed system, so the effluent could be measured to determine the fluid loss of the patient. It is the true predecessor of the positive- and negative-pressure dialysers used today.

The first commercially available dialyser was manufactured by Baxter and based on the Kolff rotating drum. It

provided a urea clearance of approximately and was based on the coil design. The priming volume was 1200–1800 ml, and this was drained into a container at the end of treatment, refrigerated, and used for priming for the next treatment. It was commercially available in 1956 for \$59.00.

The forerunner of today's dialyser was produced by Richard Stewart in 1960. The criteria for design of this hollow-fibre dialyser were low priming volume and minimal resistance to flow. The improved design contained 11 000 fibres, which provided a surface area of 1 m^2 .

Future designs for the dialyser focused on refining the solute and water removal capabilities, as well as reducing the size and priming requirements of the device, thus allowing an even higher level of precise individual care.

EMERGENCE OF HOME HAEMODIALYSIS

It was the development of Scribner's shunt (see next section on vascular access) that led to the first dialysis unit being established for patients at the University of Washington Hospital. Belding Scribner also developed a central dialysate delivery system for multiple use and set this up in the chronic care centre, which had 12 beds. These beds were quickly taken and his plan for expansion was rejected. The only alternative was to send the patients home, so the patient and family were trained to perform the dialysis and care for the shunts. Home dialysis was strongly promoted by Scribner.

Stanley Shaldon reported in 1961 that a patient dialysing at the Royal Free Hospital in London was able to self-care by setting up his own machine, initiating, and terminating dialysis (Figure 1.2); so home HD in the UK was made possible. The shunt was formed in the leg for vascular access, to allow the patient to have both hands free for the procedures. Hence, Shaldon was able to report the results of his first patient to be placed on overnight home HD in November 1964. With careful patient selection, the venture was a success. Scribner started to train patients for home at this time, and his first patient was a teenager assisted by her mother. Home dialysis was selected for this patient so that she would not miss her high-school education. The average time on dialysis was 14 hours twice weekly. To allow freedom for the patient, overnight dialysis was widely practised. At first, emphasis was on selection of the suitable patient and family, even to the extent of a stable family relationship, before the patient could be considered for home training (Baillod et al. 1965).

From these beginnings, large home HD programmes developed in the United States and the United Kingdom, thus allowing expansion of the dialysis population without increasing hospital facilities. Many patients could now be



FIGURE 1.2 Patient and nurse with dialysis machine and Kiil dialyser, 1968. *Source:* With kind permission from Science and Society Picture Library.

considered for home treatment, often with surprisingly good results, as the dialysis could be moulded to the requirements of the individual, rather than the patients conforming to a set pattern. However, with the development in the late 1970s and early 1980s of CAPD as the first choice for home treatment, the use of home HD steadily dwindled. It is now, however, seeing renewed interest. The National Institute for Clinical Excellence (NICE) published guidance on home versus hospital HD (NICE 2002) and recommended all suitable patients should be offered the choice between home HD or HD in a hospital/satellite unit. Sadly this has not led to wide-scale uptake of home HD, with only 1,396 adult patients were receiving HHD for ESKD in the UK in 2021, which represents 2.0% of the whole population who require replacement therapy for ESKD (UK Renal Registry 2023).

VASCULAR ACCESS FOR HAEMODIALYSIS

It was Sir Christopher Wren, of architectural fame, who in 1657 successfully introduced drugs into the vascular system of a dog. In 1663, Sir Robert Boyle injected successfully into humans. Prison inmates were the subjects and the cannula used was fashioned from a quill. For HD to become a widely accepted form of treatment for ESKD, a way to provide long-term access to the patient's vascular system

had to be found. Until this problem was solved, long-term treatment could not be considered. In order for good access to be established, a tube or cannula had to be inserted into an artery or vein, thus giving rise to good blood flow from the patient. The repeated access for each treatment quickly led to exhaustion of blood vessels for cannulation. The need for a system whereby a sufficiently large blood flow could be established for dialysis, without destroying a section of blood vessel every time dialysis was required, was imperative.

In the 1950s, Teschan, in the 11th Evacuation Hospital in Korea, was responsible for developing a method of heparin lock for continuous access to blood vessels. The cannulae were made from Tygon tubing and stopcocks, and the blood was prevented from clotting by irrigation with heparinised saline. It was not a loop design, as the arterial and venous segments were not joined together.

In 1960, in the United States, George Quinton, an engineer, and Belding Scribner, a physician, made use of two new synthetic polymers – Teflon and Silastic – and, using the tubing to form the connection between a vein and an artery, were able to reroute the blood outside the body (usually in the leg). This was known as the arteriovenous (AV) shunt. The tubing was disconnected at a union joint in the centre, and each tube then connected to the lines of the dialysis machine. At the end of treatment, the two ends were then reconnected, establishing a blood flow from the artery to the vein outside the body. In this way, repeat dialysis was made possible without further trauma to the vascular system.

This external shunt, whilst successful, had drawbacks. It was a potential source of infection, often thrombosed, and had a restrictive effect on the activity of the patient. In 1966, Michael Brescia and James Cimino developed the subcutaneous radial artery-to-cephalic vein AV fistula (Cimino and Brescia 1962), with Cimino's colleague, Kenneth Appel, performing the surgery.

The AV fistula required less anticoagulation, had reduced infection risk, and gave access to the bloodstream without danger of shunt disconnection. Subsequently, a number of synthetic materials have been introduced to create internal AV fistulae (grafts).

FURTHER DEVELOPMENTS

Monitoring and total control of the patient's therapy became more important as dialysis became widespread, and so equipment development has continued. Machines incorporated temperature monitoring, positive-pressure gauges, and flow meters. Negative-pressure monitoring followed, as did a wide range of dialysers with varying

surface areas, ultrafiltration capabilities, and clearance values. Automatic mixing and delivery of the dialysate and water supply to the machine greatly increased the margin of safety for the procedure and made the dialysis therapy much easier to manage. The use of microprocessors, allowing the nurse to programme a patient's requirements (such as blood flow, duration of dialysis, and fluid removal), has resulted in a prescription for an individual's needs. Average dialysis time was reduced to 4 hours, three times weekly.

The early 1970s saw the overall number of patients on kidney replacement therapy (KRT) increase due to the increased awareness brought about by the availability of treatment. Free-standing units for the sole use of kidney dialysis came into being, leading to dialysis becoming a full-time business. Committees for patient selection were disbanded, and dialysis facilities were demanded within easy reach of patients' homes. This expectation led to the emergence of small satellite units, managed and monitored by larger units, as a popular alternative to home HD treatment.

PERITONEAL DIALYSIS

Peritoneal dialysis (PD) as a form of therapy for ESKD was brought about as a result of the innovative efforts and the tenacity of many pioneers over the past two centuries. It was probably the early Egyptian morticians who first recognised the peritoneum and peritoneal cavity, with the peritoneal cavity described in 3000 BC in the Ebers papyrus as a cavity in which the viscera were somehow suspended. In Ancient Greek times, Galen, a physician, made detailed observations of the abdomen whilst treating the injuries of gladiators.

The earliest reference to what may be interpreted as PD was in the 1740s when Christopher Warrick reported to the Royal Society in London that a 50-year-old woman suffering from ascites was treated by infusing Bristol water and claret wine into the abdomen through a leather pipe (Warrick 1744). The patient reacted violently to the procedure, and it was stopped after three treatments. However, the patient was reported to have recovered and was able to walk 7 miles (13 km) a day without difficulty. A modification of this therapy was subsequently tried by Stephen Hale of Teddington in England. Two trocars were used – one on each side of the abdomen – allowing the fluid to flow in and out of the peritoneal cavity during an operation to remove ascites (Hale 1744).

Subsequent experiments on the peritoneum (Wegner 1877) determined the rate of absorption of various

solutions, the capacity for fluid removal (Starling and Tubby 1894), and evidence that protein could pass through the peritoneum. It was also noted that the fluid in the peritoneal cavity contained the same amount of urea that is found in the blood, indicating that urea could be removed by PD (Rosenberg 1916). This was followed by Putnam in 1923, suggesting that the peritoneum might be used to correct physiological problems. He observed that under certain circumstances fluids in the peritoneal cavity can equilibrate with plasma and that the rate of diffusion was dependent on the size of the molecules. At this time it was also suggested that the clearance of solutes was proportional to their molecular size and solution pH, and that a high flow rate maximised the transfer of solutes, which also depended on peritoneal surface area and blood flow (Putman 1923).

George Ganter was looking for a method of dialysis that did not require the use of an anticoagulant (Ganter 1923). He prepared a dialysate solution containing normal values of electrolytes and added dextrose for fluid removal. Bottles were boiled for sterilisation and filled with the solution, which was then infused into the patient's abdomen through a hollow needle.

The first treatment was carried out on a woman who was suffering acute kidney injury following childbirth. Between 1 and 3 l of fluid were infused at a time, and the dwell time was 30 minutes to 3 hours. The blood chemistry was reduced to within acceptable limits. The patient was sent home but, unfortunately, she died, as it was not realised that it was necessary to continue the treatment in order to keep the patient alive.

Ganter recognised the importance of good access to the peritoneum, as it was noted that it was easier to instill the fluid than it was to attain a good return volume. He was also aware of the complication of infection, and indeed it was the most frequent complication that he encountered. Ganter identified four principles, which are still regarded as important today:

1. There must be adequate access to the peritoneum.
2. Sterile solutions are needed to reduce infection.
3. Glucose content of the dialysate must be altered to remove greater volumes of fluid.
4. Dwell times and fluid volume infused must be varied to determine the efficiency of the dialysis.

There are reports of 101 patients treated with PD in the 1920s (Abbott and Shea 1946; Odel et al. 1950). Of these, 63 had reversible causes, 32 irreversible, and in 2 the diagnosis was unknown. There was recovery in 32 of 63

cases of reversible renal failure. Deaths were due to uraemia, pulmonary oedema, and peritonitis.

Stephen Rosenak, working in Europe, developed a metal catheter for peritoneal access but was discouraged by the results because of the high incidence of peritonitis. In Holland, P.S.M. Kop, who was an associate of Kolff during the mid-1940s, created a system of PD by using materials for the components that could easily be sterilised: porcelain containers for the fluid, latex rubber for the tubing, and a glass catheter to infuse the fluid into the patient's abdomen. Kop treated 21 patients and had a successful outcome with 10.

Morton Maxwell, in Los Angeles in the latter part of the 1950s, had been involved with HD, and it was his opinion that HD was too complicated for regular use. Aware of the problems with infection, he designed a system for PD with as few connections as possible. Together with a local manufacturer, he formulated a peritoneal solution and customised a container and plastic tubing set and a single polyethylene catheter. The procedure was to instill 2 L of fluid into the peritoneum, leave it to dwell for 30 minutes, and return the fluid into the original bottles. This would be repeated until the blood chemistry was normal. This technique was carried out successfully on many patients and the highly regarded results were published in 1959. This became known as the Maxwell technique (Maxwell et al. 1959). This simple form of dialysis recognised that it was no longer necessary (as with HD), to have expensive equipment with highly specialised staff in a large hospital to initiate dialysis.

THE PERITONEAL DIALYSIS CATHETER

Up to the 1970s, PD was used primarily for patients who were not good candidates for HD, or who were seeking a gentler form of treatment. Continuous flow using two catheters (Maxwell and Merrill 1953) was still sometimes used, but the single-catheter technique was favoured because of lower infection rates.

The polyethylene catheter was chosen by Paul Doolan (Doolan et al. 1959) at the Naval Hospital in San Francisco when he developed a procedure for the treatment to use under battlefield conditions in the Korean War. Because of the flexibility of the catheter, it was considered for long-term treatment. A young physician called Richard Ruben decided to try this procedure, known as the Doolan technique (Ruben et al. unpublished work), on a female patient who improved dramatically, but deteriorated after a few days without treatment. The patient was therefore dialysed repeatedly at weekends and allowed home during the week, with the catheter remaining in place. This was the

first reported long-term treatment using a permanent indwelling catheter.

PD catheters at this time were made from tubing available on the hospital ward and included gallbladder trocars, rubber catheters, whistle-tip catheters, and stainless-steel sump drains. However, as with polyethylene plastic tubes, the main challenge was kinking and blockage. Maxwell described a nylon catheter with perforations at the curved distal end, and this was the catheter that became commercially available. Advances in the manufacture of the silicone peritoneal catheter by Palmer (Palmer et al. 1964) and Gutch (Gutch 1964) included the introduction of perforations at the distal end, and later Tenckhoff included the design of a shorter catheter, a straight catheter, and a curled catheter. He also added the Dacron cuff, either single or double, to help to seal the openings through the peritoneum (Tenckhoff and Schechter 1968). He was also responsible for the introduction of the trocar that gave easy placement of the catheter. Dimitrios Oreopoulos, a Greek physician, was introduced to PD in Belfast, Northern Ireland, during his training and he noted the difficulties encountered with the catheters there. He had been shown a simple technique for inserting the catheter by Norman Dean from New York City, which allowed access to be used repeatedly.

PERITONEAL DIALYSIS AT HOME

In 1960, Scribner and Boen (Boen 1959) set up a PD programme that would allow patients to be treated at home. An automated unit was developed which could operate unattended overnight. The system used 40 L containers that were filled and sterilised at the University of Washington. The bottles were then delivered to the patient's home and returned after use. The machine was able to measure the fluid in and out of the patient by a solenoid device. An indwelling tube was permanently implanted into the patient's abdomen, through which a tube was inserted for each dialysis treatment. The system was open, and therefore was vulnerable to peritonitis. A new method was then used, whereby a new catheter was inserted into the abdomen for each treatment and removed after the treatment ended. This was still carried out in the home, when a physician would attend the patient at home for insertion of the catheter, leaving once the treatment had begun. The carer was trained to discontinue the treatment and remove the catheter. The wound was covered by a dressing, and the patient would be free of dialysis until the next week. This treatment was carried out by Tenckhoff et al. (1965) in a patient for 3 years, requiring 380 catheter punctures.

The large 40 L bottles of dialysate were difficult to handle, and delivery to the home and sterilisation were not easy. Tenckhoff, at the University of Washington, installed a water 'still' into the patient's home, to provide a sterile water supply. The water was mixed with sterile concentrate to provide the correct solution, but this method was not satisfactory as it remained cumbersome and dangerous due to the high pressure in the still. Various refinements were tried using this method, including a reverse osmosis unit, and this was widely used later for HD treatment.

Lasker, in 1961, realised the potential of this type of treatment and concentrated on the idea of a simple version by instilling 2 L of fluid by a gravity-fed system. This proved to be cheaper to maintain but was labour intensive. Later that year, he was approached by Ira Gottscho, a businessman who had lost a daughter through kidney disease, and together they designed the first peritoneal cyclor machine. The refinements included the ability to measure the fluid in and out and the ability to warm the fluid before the fill cycle. Patients were sent home using the automated cyclor treatment as early as 1970, even though there was a bias for HD at that time.

In 1969, Oreopoulos accepted a position at the Toronto Western Hospital and, together with Stanley Fenton, decided to use the Tenckhoff catheter for long-term treatment. Because of a lack of space and facilities at the hospital, it was necessary to send the patients home on intermittent PD. He reviewed the Lasker cyclor machine and ordered a supply, and by 1974 was managing over 70 patients on this treatment at home. Similar programmes were managed in Georgetown University and also in the Austin Diagnostic Clinic in the USA.

BEGINNING OF CONTINUOUS AMBULATORY PERITONEAL DIALYSIS

It was in 1975, following an unsuccessful attempt to haemodialyse a patient at the Austin Diagnostic Clinic, that an engineer, Robert Popovich, and Jack Moncrief became involved in working out the kinetics of 'long-dwell equilibrated dialysis' for this patient. It was determined that five exchanges each of 2 L day⁻¹ would achieve the appropriate blood chemistry, and that the removal of 1–2 L of fluid from the patient was needed per day. Thus came the evolution of CAPD (Popovich et al. 1976).

The treatment was so successful that the Austin group was given a grant to allow it to continue dialysing patients with CAPD. Strangely, the group's first description and account of this clinical experience was rejected by the American Society for Artificial Internal Organs. At this

time, the treatment was called 'a portable/wearable equilibrium dialysis technique'. The stated advantages compared to HD included:

- good steady-state biochemical control;
- more liberal diet and fluid intake;
- improvement in anaemia.

The main challenges were protein loss (Popovich et al. 1978) and infection. It was recognised that the source of infection was almost certainly related to the use of the bottles. Oreopoulos found that collapsible polyvinylchloride (PVC) containers for the solution were available in Canada. Once the fluid was instilled, the bag could then be rolled up and concealed under the clothing. The fluid could be returned into the bag during draining by gravity, without a disconnection taking place (Oreopoulos et al. 1978). New spike connections were produced for access to the bag of fluid, and a Luer connection for fitting to the catheter, together with tubing devised for HD, greatly reduced the chances of infection. The patients treated on an intermittent basis (by intermittent peritoneal dialysis or IPD) were rapidly converted to CAPD and evaluation of the new treatment was rapid, due to the large numbers being treated. Following approval by the US Food and Drug Administration, many centres were then able to develop CAPD programmes.

The first complete CAPD system was released to the market in 1979, giving a choice of three strengths of dextrose solution. Included in this system were an administration line and sterile items packed together to form a preparation kit, to be used at each bag change in an attempt to keep infection at bay. The regime proposed by Robert Popovich and Jack Moncrief entailed four exchanges over a 24-hour period, three dwell times of approximately 4 hours in the daytime, and 1 dwell overnight of 8 hours. This regime is the one often used today.

ADVANCES IN PERITONEAL DIALYSIS 1970s–2000s

The PD systems were continually being improved, with connectors moving from spike to Luer to eliminate as far as possible the accidental disconnection of the bag from the line. A titanium connector was found to be the superior form of adaptor for connection of the transfer set to the catheter, and probably led to a reduced infection rate (peritonitis). A disadvantage of this technique is the flow of fresh fluid down the transfer set along the area of disconnection, thus encouraging any bacteria from the disconnection to be instilled into the abdomen. The development

of the Y-system (flush before fill) in the mid-1980s in Italy resulted in a further decrease in peritonitis.

Automated PD in the form of continuous cyclic peritoneal dialysis (CCPD) was further developed by Diaz-Buxo in the early 1980s to enable patients who were unable to perform exchanges in the day to be treated with PD overnight.

Advances in CAPD included a dialysate that not only provides dialysis but that contains 1.1% amino acid, to be administered to patients who were malnourished. Those with diabetes were initially not considered for dialysis because of the complications of the disease. Carl Kjellstrand, at the University of Minnesota, suggested that insulin could be administered to those with diabetes by adding it to the PD fluid (Crossley and Kjellstrand 1971). However, this suggestion was not initially adopted because the 30-minute dwell did not give time for the drug to be absorbed into the patient. It became viable later, when long-dwell dialysis was initiated, and this gave the advantage of slow absorption, resulting in a steady state of blood sugar in the normal range, thus alleviating the need for painful injections (Flynn and Nanson 1979).

The realisation that patients are individuals, bringing their own problems associated with training, brought many exchange aid devices onto the market to assist the patient in the exchange procedure. These exchange devices were mainly used to assist such disabilities as blindness, arthritis (particularly of the hands), and patients prone to repeated episodes of peritonitis.

PERITONEAL DIALYSIS: THE PRESENT

In some centres across the world, PD is often the first choice of treatment for ESKD, because of the lack of facilities for in-centre HD. However, the relative prevalence of PD in the United Kingdom has been declining since its peak in the early 1990s, possibly because of the availability of satellite HD and concerns over PD failure in the shorter-term. At the end of 2021 in the UK, 3903 adult patients were receiving PD for ESKD, compared to 3822 in 2020, which represented 5.6% of the KRT population (UK Renal Registry 2023).

TRANSPLANTATION

IN THE BEGINNING

Kidney transplantation as a therapeutic and practical option for KRT was first reported in published literature at the turn of the twentieth century. The first steps were small and so insignificant that they were overlooked or condemned.

The first known attempts at renal transplantation on humans were made without immunosuppression between 1906 and 1923 using pig, sheep, goat, and sub-human primate donors (Elkington 1964). These first efforts were conducted in France and Germany, but others followed. None of the transplants functioned for long, if indeed at all, and the recipients all died within a period of a few hours to 9 days later.

Of all the workers at this time, the contribution made by Alexis Carrel (1873–1944) remains the most famous. His early work in Lyons, France, and in Chicago involved the transplantation of an artery from one dog to another. This work later became invaluable in the transplantation of organs. In 1906, Carrel and Guthrie, working in the Hull Laboratory in Chicago, reported the successful transplantation of both kidneys in cats and later a double nephrectomy in dogs, reimplanting only one of the kidneys. He found that the secretion of urine remained normal, and the animal remained in good health, despite having only one kidney (Carrel 1983). Carrel was awarded the Nobel Prize in 1912 for his work on vascular and related surgery.

While at this stage there was no clear understanding of the problem, some principles were clearly learned. Vascular suture techniques were reviewed and the possibility of using pelvic implantation sites was investigated and practised. No further renal heterotransplantations (animal to human) were tried until 1963, when experiments using kidneys from chimpanzee (Reemtsma et al. 1964) and baboon were tried, with eventual death of the patients. This ended all trials using animal donation.

The first human-to-human kidney transplant was reported in 1936, by the Russian Voronoy, when he implanted a kidney from a cadaver donor of B-positive blood type into a recipient of O-positive blood type, a mismatch that would not be attempted today. The donor had died 6 hours before the operation and the recipient died 6 hours later without making any urine. The following 20 years saw further efforts in kidney transplantation, all without effective immunosuppression (Groth 1972). The extraperitoneal technique developed by French surgeons Dubost and Servelle became today's standard procedure.

THE FIRST SUCCESSES

The first examples of survival success of a renal transplant can probably be attributed to David Hume, who placed the transplanted kidney into the thigh of the patient, which functioned for 5 months. Then at the Peter Bent Brigham Hospital in Boston, Massachusetts, in December 1954, the first successful identical-twin transplant was performed by the surgeon Joseph E. Murray in collaboration with the

nephrologist John P. Merrill (Hume et al. 1955). The recipient survived for more than two decades. The idea of using identical twins had been proposed when it was noted by David C. Miller of the Public Health Service Hospital, in Boston, that skin grafts between identical twins were not rejected (Brown 1937). The application of this information resulted in rigorous matching, including skin grafting, prior to effective immunosuppression.

Over the period between 1951 and 1976 there were 29 kidney transplants performed between identical twins, and the survival rate for 20 years was 50%. Studies of two successfully transplanted patients, who were given kidneys from their non-identical twins, were also reported (Merrill et al. 1960). The first survived 20 years, dying of heart disease, and the second 26 years, dying of carcinoma of the bladder. Immunosuppression used in these cases was irradiation.

IMMUNOSUPPRESSION

It was Sir Peter Medawar who appreciated that rejection is an immunological phenomenon (Medawar 1944), and this led to research into weakening the immune system of the recipients to reduce the rejection. In animals, corticosteroids, total body irradiation, and cytotoxic drug therapy were used. Experiments in animals were still far from successful, as were similar techniques when used in humans. It was concluded that the required degree of immunosuppression would lead to destruction of the immune system and finally result in terminal infections.

A few patients were transplanted between 1960 and 1961 in Paris and Boston, using drug regimens involving 6-mercaptopurine or azathioprine, with or without irradiation. They all died within 18 months. Post-mortem examination of failed kidney grafts showed marked changes in the renal histology. At first it was thought unlikely that the changes were due to immunological rejection, but later it was convincingly shown that this was indeed the underlying process.

In the early days of kidney transplantation, the kidney was removed from either a living related donor or a cadaver donor and immediately transferred to the donor after first flushing the kidney with cold electrolyte solution such as Hartman's solution. In 1967, Belzer and his colleagues developed a technique for continuous perfusion of the kidney using oxygenated cryoprecipitated plasma, which allowed the kidney to be kept up to 72 hours before transplantation. This machine perfusion required constant supervision, and it was found that flushing the kidney with an electrolyte solution and storage at 0 °C in iced saline allowed the kidney to be preserved for 24 hours or more

(Marshall et al. 1988). This was a major development in transplantation techniques.

During the 1950s, it was recognised that many of the survivors of the Hiroshima atomic bomb in 1945 suffered impairment to their immune system. It was concluded that radiation could therefore induce immunosuppression, and clinical total body irradiation was used to prolong the survival of renal transplants in Boston in 1958. This did improve the survival of some transplants; however, the overall outcomes were poor. There was clearly a need for a more effective form of immunosuppression than irradiation.

A breakthrough in immunosuppressive therapy occurred in 1962 at the University of Colorado, when it was discovered that the combination of azathioprine and prednisone allowed the prevention and in some cases reversal of rejection (Starzl et al. 1963). Transplantation could at last expand. A conference sponsored by the National Research Council and National Academy of Sciences in 1963 in Washington resulted in the first registry report, which enabled the tracing of all the early non-twin kidney recipients. In 1970, work commenced on the development of ciclosporin by Sandoz in Basel, Switzerland, following recognition of the potential (Borel et al. 1976). Clinical trials carried out in Cambridge, United Kingdom (Calne et al. 1979), showed that outcomes on renal transplantation were greatly improved, both with graft and with patient survival. Ciclosporin revolutionised immunosuppression protocols for patients who have been transplanted, even though this medication is itself nephrotoxic and its use needs close monitoring.

Tissue typing is a complex procedure. The use of united networks for organ sharing has increased the efforts of matching donor and recipient, and data available from these sources show a significant gain in survival of well-matched versus mismatched cadaver kidneys. Cross-matching remains as important today as it was at its conception. None of the immunosuppressive measures available today can prevent the immediate destruction of the transplanted organ by humoral antibodies in the hyperacute rejection phase. This was recognised as early as 1965 (Kissmeyer-Neilsen et al. 1966), and it may be that this phenomenon holds the key to the future of successful heterotransplantation.

THE PRESENT

Renal transplantation has been a dramatic success since the 1980s, with patient survival rates not less than 97% after 6 months' transplantation for both living related and cadaver transplants. At the end of 2021 in the UK, 39 189 adult patients were living with a kidney transplant for ESKD, which represented 56.4% of the KRT population.

THE FUTURE

There is no doubt that renal transplantation is the ‘gold standard’ for patients requiring KRT. giving, in general, a better quality of life than dialysis. However, donor organs remain in short supply, despite changes in UK law and in other countries (see Chapter 9). Encouragingly, there was a 15% increase in kidney transplants performed in the UK 2021 compared with 2020, with an increase in transplants from living donors by 36%, although transplant activity has not yet recovered to pre-pandemic levels (UK Renal Registry 2023).

CONCLUSION

Kidney replacement therapy has come a long way from the small beginnings of the hot baths in Rome. Refinements and improvements continue, but the challenge of providing acceptable person-centered therapies for all who need treatment for ESKD remains.

In summary, UK Renal Registry data (2023) report that in the United Kingdom at the end of 2021:

- 8,175 adult patients started KRT for ESKD in the UK in 2021, an increase of 7.3% from 2020.
- The incidence of kidney replacement therapy in adults was 154 pmp.
- The median age of patients receiving KRT was 63.7 years but varied with ethnicity (White 65.6 years; Asian 61.8 years; and Black 57.8 years).
- Diabetes remains the most common identifiable primary kidney disease and continues to account for an increasing proportion of patients starting KRT (31.3%).
- In 2021, 21% of patients started KRT on PD, compared to 21.8% in 2020. This is still a higher proportion than previous years.
- In 2021, only 5.8% of patients started KRT with a transplant, lower than previous years and likely due to ongoing COVID-related disruption.
- In summary, Figure 1.3 shows treatment modality of adult patients receiving KRT in 2020.

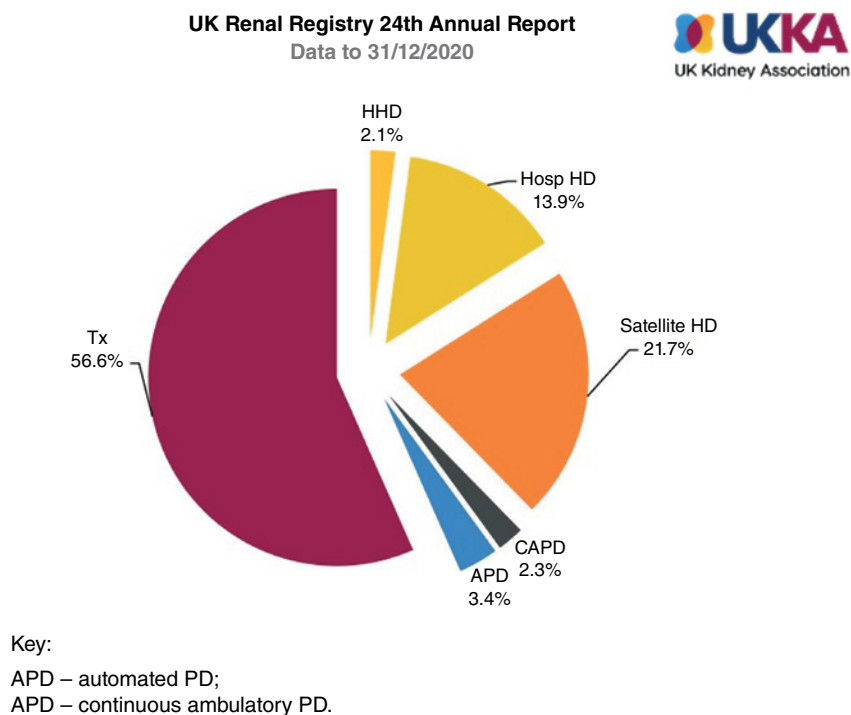


FIGURE 1.3 Treatment modality of adult patients receiving KRT in the UK (not including data from Scotland) on 31/12/2020.

Note: The data reported by the UK Renal Registry have been supplied by the UKRR of the UK Kidney Association. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the UKRR or the UK Kidney Association.

REFERENCES

- Abbott, W.E. and Shea, P. (1946). Treatment of temporary renal insufficiency (uraemia) by peritoneal lavage. *American Journal of the Medical Sciences* 211: 312.
- Abel, J.J., Rowntree, L.G., and Turner, B.B. (1914). The removal of diffusible substances from the circulating blood of living animals by dialysis. *Journal of Pharmacology and Experimental Therapeutics* 5: 275–316.
- Baillod, R.A., Comty, C., Ilahi, M. et al. (1965). *Proceedings of the European Dialysis and Transplant Association* 2, 99. Amsterdam: Excerpta Medica.
- Boen, S.T. (1959). *Peritoneal Dialysis*, 26. Amsterdam: Van Gorcum.
- Borel, J.F., Feurer, C., Gubler, H.U. et al. (1976). Biological effects of cyclosporin A. A new antilymphocytic agent. *Agents and Actions* 6: 468–475.
- Brown, J.B. (1937). Homografting of the skin. With report of success in identical twins. *Surgery* 1: 558–563.
- Byrne, C., Caskey, F., Castledine, C. et al. (2018). The twentieth annual report of the UK Renal Registry, Bristol. *Nephron* 139 (suppl1): 13–46.
- Calne, R.Y., Rolles, K., White, D.J.G. et al. (1979). Cyclospor A initially as the only immunosuppressant in 34 recipients of cadaveric organs: 32 kidneys, 2 pancreases, and 2 livers. *Lancet* 1: 1033–1036.
- Carrel, A. (1983). Results of the transplantation of blood vessels, organs and limbs. *JAMA* 250: 994–953.
- Cimino, J.E. and Brescia, M.J. (1962). Simple venepuncture for haemodialysis. *New England Journal of Medicine* 267: 608–609.
- Crossley, K. and Kjellstrand, C.M. (1971). Intraperitoneal insulin for control of blood sugar in diabetic patients during peritoneal dialysis. *British Medical Journal* 1: 269–290.
- Doolan, P.D., Murphy, W.P. Jr., Wiggins, R.A., et al. (1959). An evaluation of intermittent peritoneal lavage. *American Journal of Medicine* 26: 831–844.
- Eggerth, A.H. (1921). The preparation and standardization of collodion membranes. *Journal of Biological Chemistry* 48 (1): 203–221.
- Elkington, J.R. (1964). Moral problems in the use of borrowed organs artificial and transplanted. *Annals of Internal Medicine* 60: 309–313.
- Fishman, A.P., Kroop, I.G., Leiter, H.E. et al. (1948). Management of anuria in acute mercurial intoxication. *NY State Journal of Medicine* 48: 2393–2396.
- Flynn, C.T., and Nanson, J.A. (1979). Intraperitoneal insulin with CAPD – an artificial pancreas. *Transactions of the American Society of Artificial Internal Organs* 25: 114–117.
- Ganter, G. (1923). About the elimination of poisonous substances from the blood by dialysis. *Münchener Medizinische Wochenschrift* (1950) 70: 1478–1480.
- Graham, T. (1854). The Bakerian lecture – on osmotic force. *Philosophical Transactions of the Royal Society of London* 144: 177–228.
- Groth, C.G. (1972). Landmarks in clinical renal transplantation. *Surgery, Gynecology & Obstetrics* 134: 323–328.
- Gutch, C.F. (1964). Peritoneal dialysis. *Transactions of the American Society of Artificial Internal Organs* 10: 406–407.
- Hale, S. (1744). A method of conveying liquors into the abdomen during the operation of tapping. *Philosophical Transactions of the Royal Society* 43: 20–21.
- Hess, C.L.V. and McGuigan, H. (1914). The condition of the sugar in the blood. *Journal of Pharmacology and Experimental Therapeutics* 6: 45–55.
- Hume, D.M., Merrill, J.P., Miller, B.F., et al. (1955). Experience with renal homotransplantation in the human. Report of nine cases. *Journal of Clinical Investigation* 34: 327–382.
- Kissmeyer-Neilsen, F., Olsen, S., Peterson, V.P., et al. (1966). Hyperacute rejection of kidney allografts, associated with pre-existing humoral antibodies against donor cells. *Lancet* 2: 662–665.
- Kolff, W.J. (1950). Artificial kidney – treatment of acute and chronic uraemia. *Cleveland Clinic Quarterly* 17: 216–228.
- Kolff, W.J. (1965). First clinical experience with the artificial kidney. *Annals of Internal Medicine* 62: 608–619.
- Kolff, W.J. and Berk, H.T. (1944). The artificial kidney: a dialyser with a great area. *Acta Medica Scandinavica* 117: 121–134.
- Legrain, M. and Merrill, J.P. (1953). Short term continuous transperitoneal dialysis. *New England Journal of Medicine* 248: 125–129.
- MacNeill, A.E. (1949). Some possible uses of blood dialysers. Surgeons practice meeting, 23 September 1949, Bretton Woods, NH, *Proceedings of the New England Surgical Society*, p. 3.
- Malinow, M.R. and Korzon, W. (1947). Experimental method for obtaining an ultrafiltrate of the blood. *Journal of Laboratory and Clinical Medicine* 31: 461–471.
- Marshall, V.C., Jablonski, P., and Scott, D.F. (1988). Renal preservation. In: *Kidney Transplantation: Principles and Practice*, 3e (ed. P.J. Morris), 151–182. Philadelphia, PA: W.B. Saunders.
- Maxwell, M.H., Rockney, R.E., and Kleeman, C.R. (1959). Peritoneal dialysis, techniques and application. *JAMA* 170: 917–924.
- Medawar, P.B. (1944). The behaviour and fate of skin autografts and skin homografts in rabbits. *Journal of Anatomy* 78: 176–199.
- Merrill, J.P., Murray, J.E., Harrison, J.H. et al. (1960). Successful homotransplantation of the kidney between non-identical twins. *New England Journal of Medicine* 262: 1251–1260.
- Merrill, J.P., Thorn, G.W., Walter, C.W. et al. (1950). The use of an artificial kidney. 1. Technique. *Journal of Clinical Investigation* 29: 412–424.
- National Institute for Clinical Excellence (2002). Guidance on Home compared with Hospital Haemodialysis for Patients with

- End-Stage Renal Failure 2002, Technology Appraisal No. 48. <https://www.nice.org.uk/guidance/ta48> (accessed 3 April 2024).
- Odel, H.M., Ferris, D.O., and Power, H. (1950). Peritoneal lavage as an effective means of extrarenal excretion. *American Journal of Medicine* 9: 63–77.
- Opelz, G. and Terasaki, P.I. (1974). Poor kidney transplant survival in recipients with frozen-blood transfusions or no transfusions. *Lancet* 2: 696–698.
- Oreopoulos, D.G., Robson, M., Izatt, S. et al. (1978). A simple and safe technique for continuous ambulatory peritoneal dialysis. *Transactions of the American Society of Artificial Organs* 24: 484–489.
- Palmer, R.A., Quinton, W.E., and Gray, J.F. (1964). Prolonged peritoneal dialysis for chronic renal failure. *Lancet* 1: 700–702.
- Palmer, R.A. and Rutherford, P.S. (1949). Kidney substitutes in uraemia: the use of Kolff's dialyser in two cases. *Canadian Medical Association Journal* 60: 261–266.
- Popovich, R.P., Moncrief, J.F., Dechard, J.F., et al. (1976). The definition of a novel portable/wearable equilibrium peritoneal dialysis technique. *Abstracts of the Transactions of the American Society of Artificial Organs* 5: 64.
- Popovich, R.P., Moncrief, J.W., Nolph, K.D. et al. (1978). Continuous ambulatory peritoneal dialysis. *Annals of Internal Medicine* 88: 449–456.
- Putman, T. (1923). The living peritoneum as a dialysing membrane. *American Journal of Physiology* 63: 548–555.
- Reemtsma, K., McCracken, B.H., Schlegel, J.U. et al. (1964). Renal heterotransplantation in man. *Annals of Surgery* 160: 384–410.
- Richardson, B.W. (1889). Practical studies in animal dialysis. *Asclepiad* 6: 331–332.
- Rosenberg, M. (1916). Nitrogenous retention of substances in the blood and in other body fluids in the core of the kidneys. *Berlin Klinischen Wochenschrift* 53: 1314–1316.
- Skeggs, L.T. Jr., Leonards, J.R., and Heisler, C.R. (1949). Artificial kidney: 11. Construction and operation of an improved continuous dialyser. *Proceedings of the Society for Experimental Biological Medicine* 72 (3): 539–543.
- Starling, E.H. and Tubby, A.H. (1894). On the paths of absorption from the peritoneal cavity. *Journal of Physiology* 16: 140.
- Starzl, T.E., Marchioro, T.L., and Waddell, W.R. (1963). The reversal of rejection in human renal homografts with subsequent development of homograft tolerance. *Surgical and Gynecological Obstetrics* 117: 385–395.
- Tenckhoff, H., and Schechter, H. (1968). A bacteriologically safe peritoneal access device. *Transactions of the American Society of Artificial Internal Organs* 14: 181–186.
- Tenckhoff, H., Shilipetar, G., and Boen, S.T. (1965). One year experience with home peritoneal dialysis. *Transactions of the American Society of Artificial Internal Organs* 11: 11–14.
- Teschan, P.E. (1955). Haemodialysis in military casualties. *Transactions of the American Society of Artificial Internal Organs* 2: 52–54.
- Thalhimer, W., Solandt, D.Y., and Best, C.H. (1938). Experimental exchange transfusion using purified heparin. *Lancet* 11: 554–555.
- Warrick, C. (1744). An improvement in the practice of tapping, whereby that operation instead for the relief of symptoms, became an absolute cure for ascites, exemplified in the case of Jane Roman. *Philosophical Transactions of the Royal Society* 43: 12–19.
- Wegner, G. (1877). Surgical comments on peritoneal cavity with special emphasis on ovariectomy. *Archives of Klinischen Chirurgia* 20: 53–145.
- UK Renal Registry (2023) UK Renal Registry 25th Annual Report – data to 31/12/2021, Bristol, UK. Available from <https://ukkidney.org/audit-research/annual-report>

Applied Anatomy and Physiology, the Kidney Disease Process, and Kidney Investigations

Claire Carswell and Stephen O'Neil

Queen's University Belfast, Belfast, UK

LEARNING OUTCOMES

- to understand the structure and main functions of the kidney, including the basic renal processes of filtration, reabsorption, and secretion.
- to identify the main conditions causing advanced kidney disease, and analyse the clinical features of these conditions.
- to explain the procedures commonly undertaken in the diagnosis of acute kidney injury (AKI) and chronic kidney disease (CKD).
- to gain knowledge and understanding of the investigations required in the diagnosis of renal impairment and provide a rationale for the use of these investigations and procedures.

INTRODUCTION

This chapter provides the reader with a detailed discussion of all aspects of renal physiology and its relationship to important pathophysiological processes in renal disease, and the investigations and procedures for diagnosing kidney conditions.

The first part of the chapter explores the normal renal anatomy and physiology as well as disease processes causing advanced kidney disease. The second part describes the investigations and procedures used in diagnosing acute kidney injury and chronic kidney disease. This is not intended as a complete reference to all kidney diseases; rather, it illustrates how altered renal physiology can affect the whole body, how other diseases can affect kidney function, and how some kidney conditions can be investigated.

STRUCTURE AND FUNCTIONS OF THE KIDNEY

The kidneys are paired organs lying in the retroperitoneum, on either side of the vertebral column. The upper pole of the kidney is at the spinal level of T12 and the lower pole at approximately L3. The right kidney is a little lower due to the presence of the liver on that side. Each kidney is approximately 11 cm long and weighs about 150 g (Figure 2.1).

On the concave surface of the kidney lies the hilum, from which the ureter and the main blood vessels and nerves access the kidney. The cut surface of the kidney reveals two distinct regions: a dark outer region called the cortex and a pale inner region called the medulla. The outer cortex is covered by a fibrous capsule and the whole kidney is surrounded by a pad of fat (Gerota's fascia) that offers some protection against injury. Broadly speaking, the cortex contains the filtering and reabsorptive components of the

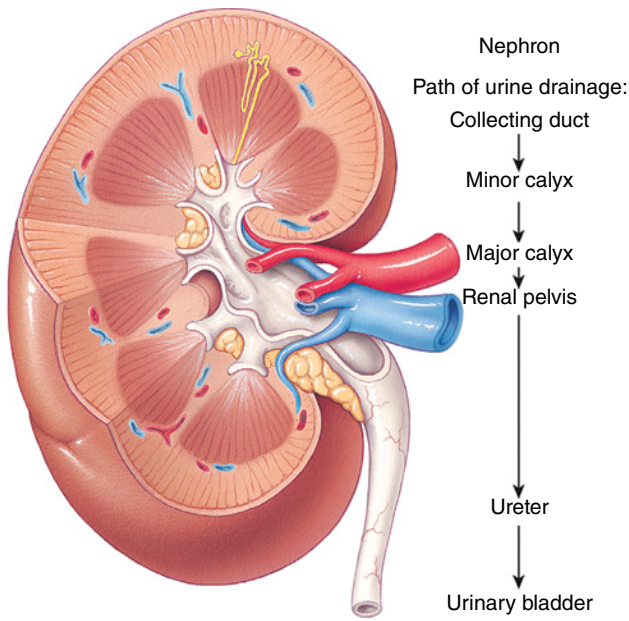


FIGURE 2.1 Structure of the kidney. *Source:* Tortora and Derrickson (2007). This material is reproduced with permission of John Wiley & Sons, Inc.

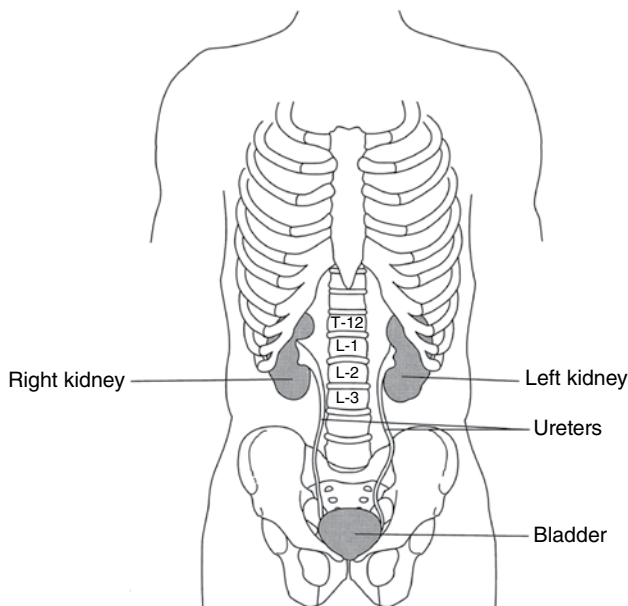


FIGURE 2.2 Relative position of the kidneys in the body.

nephrons, whilst the medulla contains the concentrating and diluting components of the nephrons and a system of collection ducts. These ducts funnel the urine into the pelvis at the heart of the medulla, from where it moves down the ureter into the bladder (Figure 2.2).

THE NEPHRON

The nephron is the functional unit of the kidney, and each kidney contains approximately 1 million nephrons (Figure 2.3). The structure of the nephron is related to its complex functions and contains five components, each performing a distinct process:

- the Bowman's capsule – forming a blind-ending capsule around a knot of capillaries called the glomerulus (site of filtration);
- the proximal convoluted tubule (site of bulk-phase reabsorption and some secretion);
- the loop of Henle (where concentration and dilution of urine mainly occurs);
- the distal convoluted tubule (the site of 'fine-tuning' reabsorption and more secretion);
- the collecting duct (also important for the concentration of urine and carrying urine into the renal pelvis).

These processes are interdependent and intimately related to each other by the shape of the nephron.

There are broadly two types of nephron found in the kidney (Figure 2.4). Approximately 85% of nephrons are cortical nephrons, which have short loops of Henle that are contained in the cortex of the kidney. The other 15% of nephrons are juxtamedullary nephrons and they have long loops of Henle, which extend deep into the medulla of the kidney. The long loops of Henle enable concentration of urine and conservation of water. The loops of Henle, together with the collecting ducts (which also pass through the medulla), give the pyramids of the medulla a striated appearance.

The main functions of the kidney are to rid the body of the end-product of metabolism and regulate the electrolytes found in the body fluids. A more detailed list of the functions of the kidney can be found in Box 2.1.

VERSATILITY OF URINE

Broadly speaking, there are three parameters that can vary to maintain the constancy of our bodily fluids: urinary volume, urinary concentration, and urinary content.

URINARY VOLUME

In a healthy person, the volume of urine produced per day can vary from as little as 300 ml, if no water is ingested or there is excessive water loss (as in diarrhoea), up to a maximum of 23l in cases of excessive fluid ingestion. In healthy people, urine output should not drop below

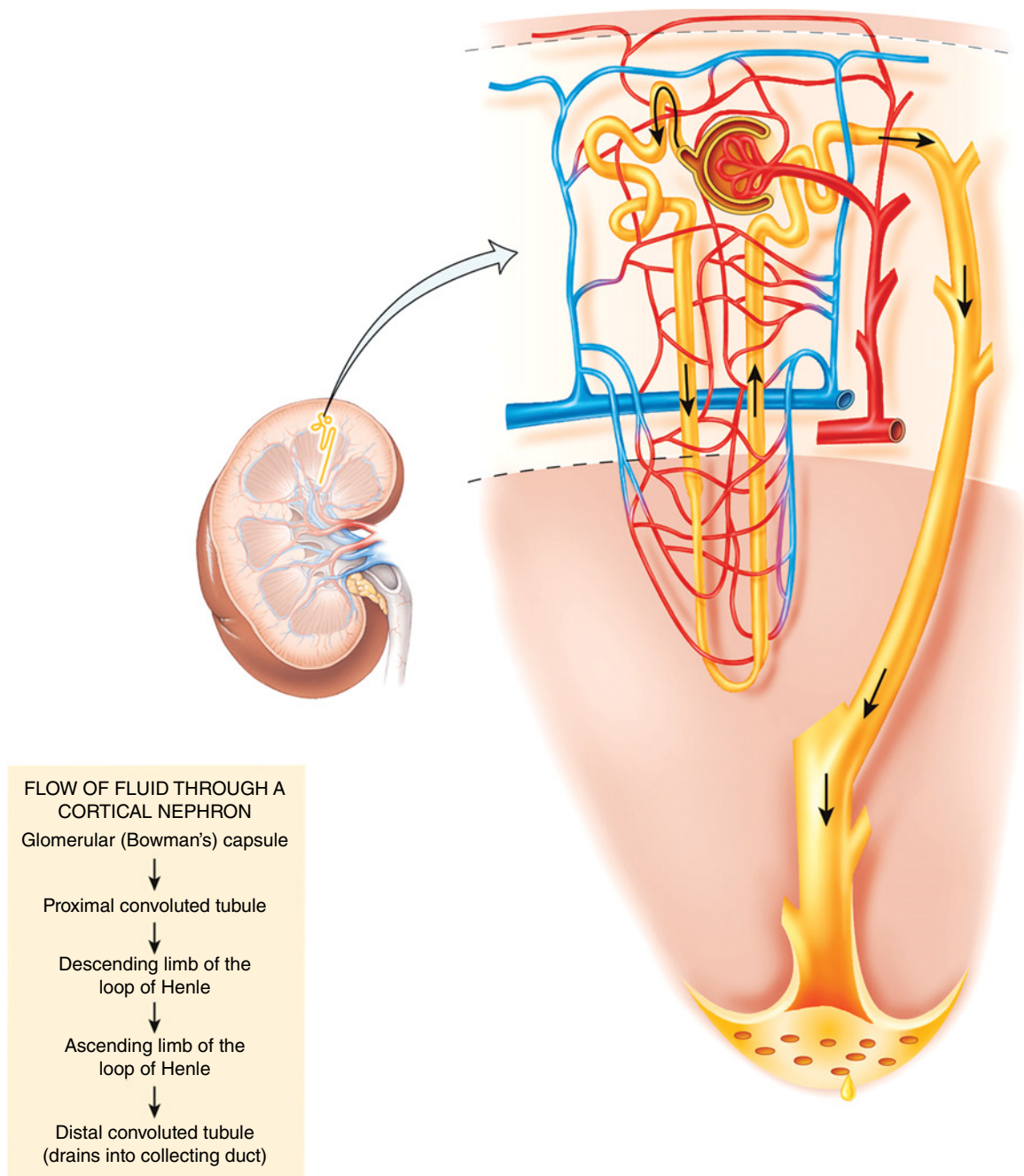


FIGURE 2.3 The parts of a nephron, collecting duct, and associated blood vessels. *Source:* Tortora and Derrickson (2007). This material is reproduced with permission of John Wiley & Sons, Inc.

300 ml per day because this is the absolute minimum water volume required to excrete the daily load of waste products. If the amount of waste products to be removed by the kidney rises, then the minimum urine volume must also rise. However, the average urine output per day is approximately 1500 ml. The kidneys' ability to vary the

volume of daily urine output over such a wide range is essential if we are to maintain a constant body fluid volume in the face of adverse factors such as excessive heat, which causes sweating; colonic infections causing diarrhoea; or excessive thirst and water ingestion, as seen in the condition psychogenic polydipsia (Table 2.1).

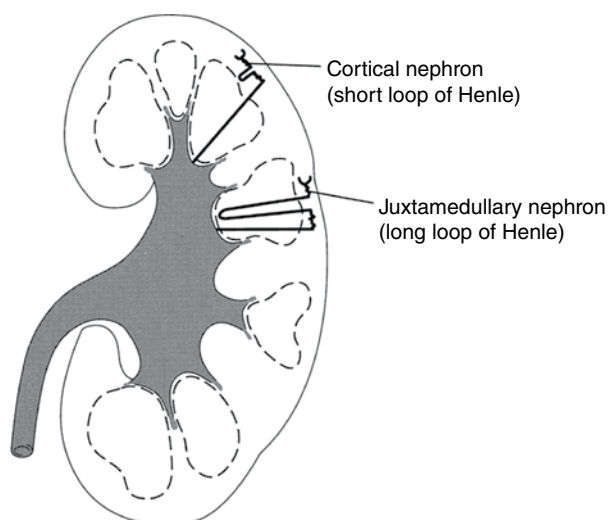


FIGURE 2.4 The position of the nephrons in the kidney.

BOX 2.1

THE FUNCTIONS OF THE KIDNEY

Excretory

- Excretion of metabolic waste products (e.g. urea and creatinine)

Regulatory

Regulation of:

- Body water volume
- Body fluid osmolality
- Electrolyte balance
- Acid–base balance
- Blood pressure

Metabolic

- Activation of vitamin D
- Production of renin
- Production of erythropoietin

Table 2.1 Normal fluid inputs and outputs.

Inputs (ml)		Outputs (ml)	
Water	1500	Urine ^a	1500
Food	500	Insensible loss lungs	400
		skin ^b	400
Water of metabolism	400	Faeces ^c	100
Total	2400		2400

^aUrinary volume is the only factor that can be regulated by the body to balance fluid inputs.

^bThis insensible loss of fluid through the skin is by simple evaporation (not sweat). Sweat is called 'sensible loss' and may reach up to 5 l per hour, for example, when a person is exercising excessively.

^cLoss of fluid with the faeces can be as high as several litres per day in the presence of severe intestinal infections such as cholera.

urine. On a hot summer's day with little fluid intake, urine is dark in colour and of low volume, whereas if liberal amounts of beer have been consumed at a party, large volumes of watery urine are passed all evening.

The ability of the kidneys to excrete excess solutes in varying amounts of water by concentrating or diluting the urine is essential for maintaining a constant body osmolality (Box 2.2). The mechanism that controls the concentration or dilution of urine is often affected early on in renal disease, making it difficult to control both body fluid volume and osmolality in response to changes in fluid inputs and outputs. This can result in the individual tipping back and forth from states of dehydration to fluid overload.

URINARY CONTENT

The range of substances that can be constituents of urine is varied and includes:

- *Ions.* These include sodium, potassium, calcium, magnesium, chloride, bicarbonate, phosphate, and ammonium.
- *Metabolic waste.* Urea, creatinine, and uric acid are all waste.
- *Drug metabolites.* Most metabolites of pharmacological agents are eventually excreted from the body through the kidneys; many are detoxified in the liver first.
- *Other products of normal metabolism.* Metabolites of hormones can be detected in the urine by appropriate assays and may be a diagnostic aid.

Normal urine is clear in appearance, though it may vary in colour from pale to dark amber, depending on its concentration. Finally, normal urine has a pH that is

URINARY CONCENTRATION

Though the volume of urine can vary over a wide range, the amount of solutes to be excreted by the kidney each day is much less variable. Thus, to excrete a fairly fixed volume of solutes each day in a variable volume of water, the kidney must have the ability to concentrate or dilute the

BOX 2.2**CONCEPTS OF OSMOSIS AND BODY OSMOLALITY**

- Water can move between the different body fluid compartments across semipermeable membranes by the process of osmosis.
- The more concentrated a solution, the more water will be drawn into this solution.
- Any solute that can cause the movement of water across a semipermeable membrane is said to be 'osmotically active'.
- The osmotic activity of substances in solution is dependent on the number of dissolved particles in the solution and not on their size or charge.
- Sodium chloride (NaCl) dissociates in solution into Na^+ and Cl^- ions, so the number of osmotically active particles is almost double the number of NaCl molecules (but not exactly double because the dissociation is not complete; the solution consists of NaCl, Na^+ , and Cl^- particles).
- Osmotically active particles in solution are measured by the unit called the osmole or milliosmole (mosm).
- Osmolality is measured in mosm per kg water and is a measure of the potential osmotic activity of dissolved solutes in solution.
- Normal body fluid osmolality is 285 mosm per kg water.
- The concentration (rather than the osmotic activity) of individual electrolytes is measured in mmol (millimoles) or μmol (micromoles) rather than mosmol

slightly acidic – around pH 6 – though urine can have a pH in the range 4.0–8.0 in cases of severe acidosis or alkalosis, respectively.

BASIC RENAL PROCESSES

GLOMERULAR FILTRATION

This is a process of filtration of plasma across the glomerular basement membrane from the glomerulus into the Bowman's capsule (Figure 2.5). The glomerular filtration surface is a unique structure composed of three layers:

1. The endothelial lining of the glomerular capillaries.
2. The basement membrane.
3. The epithelial cells of the Bowman's capsule, or podocytes. Filtration occurs between the slits formed by the finger-like processes of these cells (called pedicels), which surround glomerular capillaries.

These three layers are fused together and act as a barrier to the filtration of large-molecular-weight molecules, such as proteins.

Blood enters the glomerulus from branches of the renal artery, ending in the afferent arteriole. Blood then

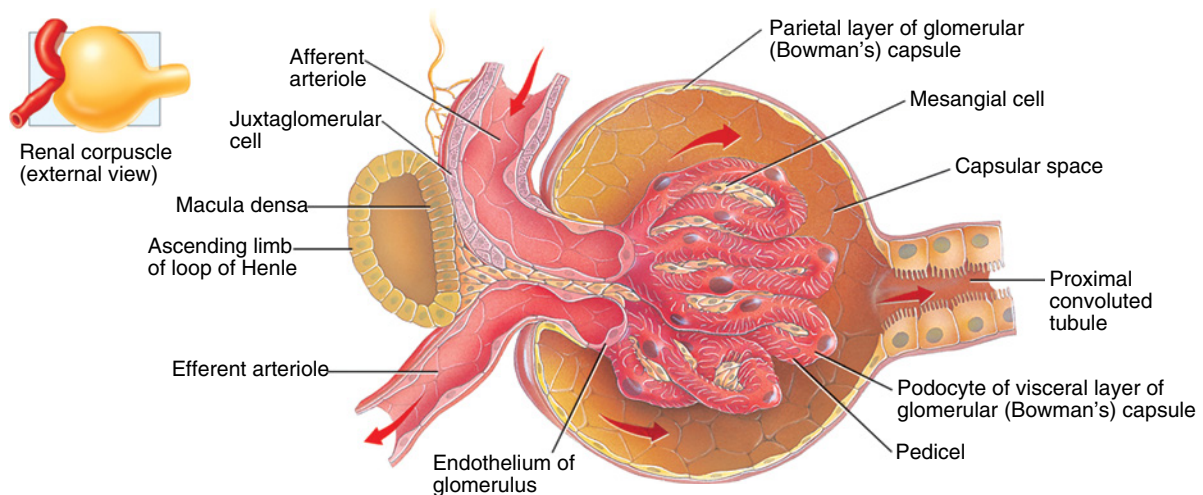


FIGURE 2.5 Structure of the glomerulus and Bowman's capsule. *Source:* Tortora and Nielsen (2009). This material is reproduced with permission of John Wiley & Sons, Inc.

leaves the glomerulus through the efferent arteriole rather than a vein. In most nephrons (those in the cortex), the efferent arteriole from the glomerulus divides into capillaries, which cover the surfaces of the convoluted tubules. The capillaries finally empty into the venous system. In the deeper juxtamedullary nephrons, the efferent arteriole divides to form loops that lie parallel to the loops of Henle and so run down into the medulla. These vessels are called the vasa recta and are concerned with the process of concentration of the urine. Blood then leaves the kidney through a series of larger converging veins, ending in the renal vein, which returns the blood to the vena cava.

In effect, the nephrons contain two capillary beds, one within the glomerulus and a second that surrounds the convoluted tubules of the nephrons. This unusual arrangement of two capillary beds enables a pressure gradient to exist within the nephron, with high pressure in the glomerulus, favouring filtration, and relatively low pressure in the peritubular capillaries, favouring reabsorption.

The formation of a filtrate from plasma flowing through the glomerulus occurs due to Starling's forces. In the glomerulus, filtration depends on three main pressures. One type of pressure promotes filtration, and the other pressures oppose filtration. Fluid is forced across the glo-

merular basement membrane because of the high hydrostatic pressure of blood flowing through the afferent arteriole. This pressure is greater than the sum of the blood colloid osmotic pressure (BCOP) and the pressure in the Bowman's capsule (capsular hydrostatic pressure) opposing it (Figure 2.6). In an ordinary capillary bed, this filtrate would be almost entirely reabsorbed back into the capillary at the venule end because the hydrostatic pressure would have fallen to below the colloid osmotic pressure of the capillary, which would then pull the fluid back in by osmosis. However, in the glomerulus, because blood leaves via another arteriole (the efferent arteriole) rather than a venule, a high hydrostatic pressure is maintained and the sum of the BCOP and capsular hydrostatic pressure is insufficient to move fluid back into the capillary. This situation is obviously desirable so that large amounts of filtrate can be made. All of the filtrate formed in the glomerulus passes into the Bowman's capsule and is often referred to as tubular urine or fluid.

Amount and composition of glomerular filtrate

The amount of glomerular filtrate formed per minute is referred to as the glomerular filtration rate (GFR), and in the average healthy person is approximately 125 ml per min.

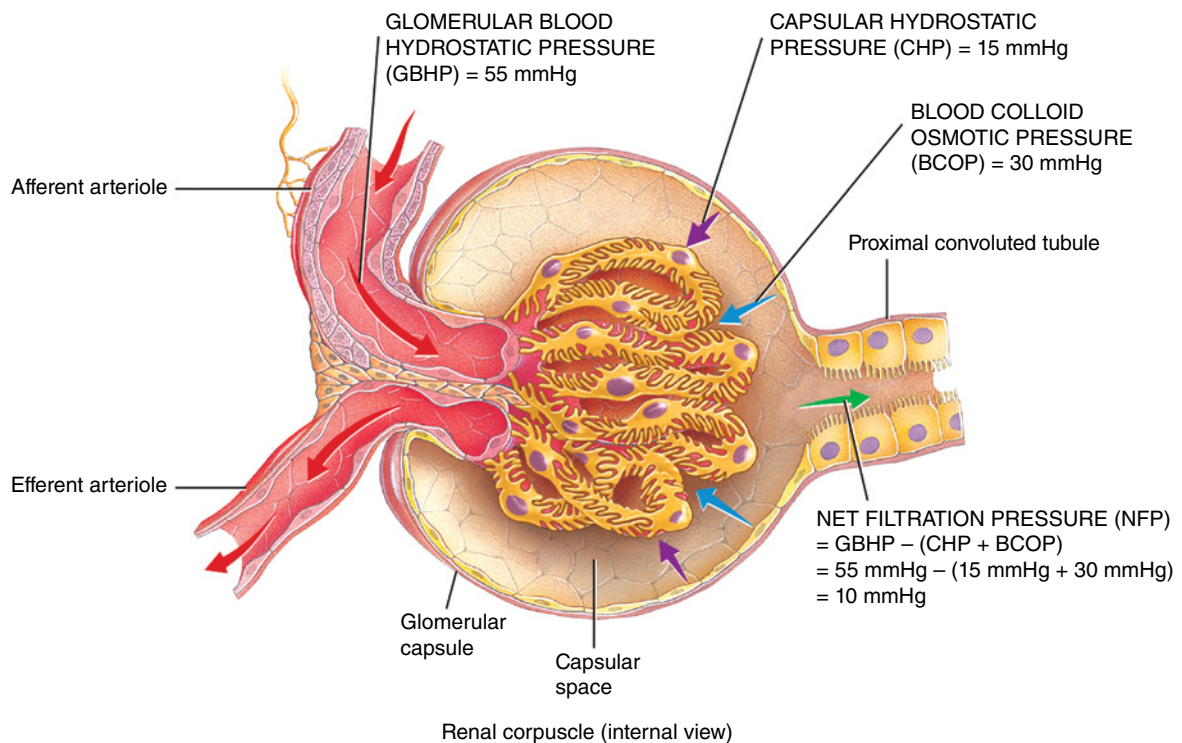


FIGURE 2.6 The formation of filtrate in the glomerulus. *Source:* Jenkins and Tortora (2013).

This volume is the sum amount from all 2 million nephrons in the kidneys and thus the amount from each nephron is relatively small. A quick calculation shows that at a GFR of 125 ml per min, the total amount of filtrate formed per day is 180 l – approximately 60 times the circulating plasma volume. Obviously, the majority of this must be reabsorbed to prevent severe dehydration.

The composition of the initial glomerular filtrate is that of a plasma ultrafiltration; that is, without proteins. The main determinant of what can pass through the glomerular basement membrane is molecular size, although the molecular shape and charge are also important. Strongly negatively charged molecules, such as albumin, tend to be repelled because of the presence of fixed negative charges in the basement membrane. Albumin can cross the filter but does so only in minute quantities since it is hindered by its negative charge. Similarly, haemoglobin, with a molecular weight of 68 000, is small enough to be filtered, whereas intact erythrocytes are too large to cross into the Bowman's capsule. The appearance of haemoglobin in urine therefore indicates haemolysis, with the release of the protein into the blood. It is because of this free permeability of small molecules that the composition of the initial glomerular filtrate is the same as that of the plasma, and will include the major ions sodium, potassium, chloride, bicarbonate, calcium, and phosphate; glucose; amino acids; and the toxic waste products of urea and creatinine. Any albumin filtered is reabsorbed through the proximal tubule into the renal lymph system and returned to the bloodstream.

Estimated glomerular filtration rate (eGFR)

The 'average' GFR quoted based on young adults. Children have a lower GFR than this because their nephrons are still increasing in size (all nephrons are present at birth). After 30 years, the number of functioning nephrons starts to decrease; thus, the GFR decreases proportionately. However, this only becomes significant to health when the GFR falls by around 5 ml per min – a situation that only occurs in kidney disease. An estimated GFR (eGFR) can be calculated by measuring serum creatinine and applying a formula.

SELECTIVE REABSORPTION

Reabsorption is a process that involves the movement of water and dissolved substances from the tubular fluid back into the bloodstream. The term *selective* infers a regulatory function to this process, as not all filtered substances are returned to the blood. Any substances not reabsorbed will pass with the urine into the bladder to be

excreted from the body. The main sites for reabsorption in the nephron are the proximal and distal convoluted tubules.

Mechanisms of reabsorption

There are three main mechanisms in the nephron for the reabsorption of water and solutes: osmosis, diffusion, and active transport. Osmosis is the movement of water from an area of low concentration to an area of high concentration across a semipermeable membrane, which allows water molecules through but is selectively permeable to solute molecules.

Diffusion occurs where a more concentrated solution meets one that is less concentrated. The solute will equilibrate throughout the solvent. This may occur across a membrane so long as the membrane is permeable to the solute. Diffusion may also occur through specialised 'protein carriers' in the membrane. This is sometimes known as *facilitated diffusion*. In these cases, the number of protein carriers in the membrane is limited, meaning that movement of the solute will be limited. This is true for tubular reabsorption of glucose. Once all the carriers are active, reabsorption of glucose has reached its maximum. If the filtered load of glucose is excessive, not all can be reabsorbed and glucose will appear in the urine, as happens in untreated diabetes mellitus.

Active transport is so named because it is an energy-requiring process. The energy source is adenosine triphosphate (ATP). Active transport can move solutes against a concentration gradient. Cells that carry out a lot of active transport will have a lot of mitochondria present (the 'power-generating' organelles of cells).

In the proximal tubule cells, where most reabsorption is by active transport, the cells are packed with mitochondria. Proximal tubule cells also have a large brush border on their luminal surface (the surface facing into the tubule) to increase their surface area for reabsorption. In contrast, cells lining the descending loop of Henle are comparatively thin, have no brush border, and have relatively few mitochondria. These cells are not very metabolically active and are adapted for reabsorption by passive diffusion. The epithelial cells of the distal tubule are similar to those of the proximal tubule but with a less well-defined brush border and fewer mitochondria. This suggests that these cells are capable of active transport of substances but in much lesser quantities than in the proximal tubule. This again illustrates how each segment of the nephron is anatomically adapted to carry out its unique functions. The different cell types lining the tubules are illustrated in Figure 2.7.

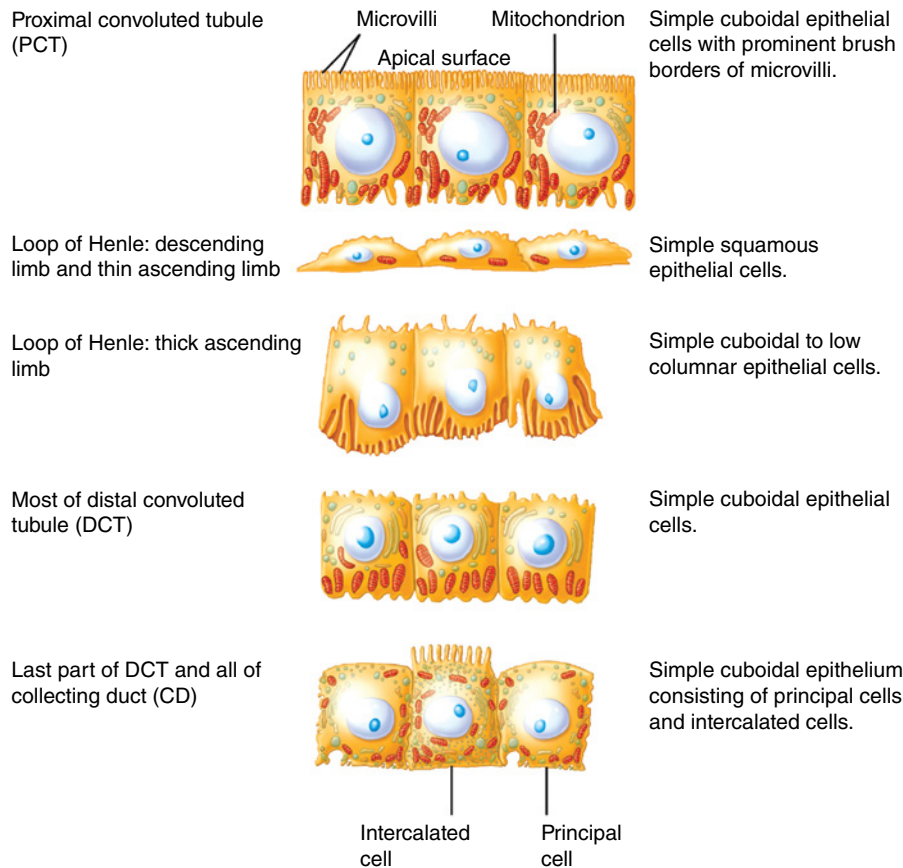


FIGURE 2.7 Histological features of the renal tubule and collecting duct. *Source:* Tortora and Nielsen (2009). This material is reproduced with permission of John Wiley & Sons, Inc.

Reabsorption in the proximal convoluted tubule – the site of bulk-phase reabsorption

Approximately 65% of all reabsorption occurs in the proximal tubule (hence the term *bulk phase*) and is obligatory rather than regulatory. Most substances here are reabsorbed by active transport mechanisms, including sodium, chloride, potassium, glucose, amino acids, phosphate, and bicarbonate. Urea is absorbed by passive diffusion and water is reabsorbed by osmosis. Some substances are reabsorbed almost entirely in the proximal tubule, such as glucose and amino acids, which do not appear in the urine, whereas others have only between 60% and 70% reabsorption, such as sodium, water, and potassium. Approximately 50% of urea is reabsorbed here but creatinine is not reabsorbed at all.

Reabsorption in the distal convoluted tubule – the site of fine-tuning reabsorption

This is the site where more specific regulation of substances occurs according to the needs of the body. For the distal

tubule to be aware of precisely what the body's needs are, there has to be communication between the cells of the distal tubule and the rest of the body. This communication occurs via a range of hormones that form part of a negative-feedback system for the homeostatic control of ions and water. For example, sodium and water reabsorption are under the control of aldosterone (secreted by the adrenal cortex) and ADH secreted by the posterior pituitary gland. Potassium reabsorption is also controlled by aldosterone, whereas calcium and phosphate are controlled by parathyroid hormone (PTH). The precise mechanisms for controlling the electrolytes outlined above will be dealt with in later sections in this chapter.

SECRETION

The process of secretion occurs in both the proximal and distal tubules and involves the movement of substances from blood flowing through the peritubular capillaries, through the tubule wall cells, and into the tubular fluid.

Secretion is the opposite process to reabsorption. Substances that are secreted into the tubules are excreted in the urine. Though creatinine is freely filtered at the glomerulus, total creatinine excretion is increased by 20% by the process of secretion. Ions that are transported into the tubules by secretion are hydrogen, which is secreted in both the proximal and distal tubules and is important in acid–base control, and potassium, which is secreted in the distal tubule in exchange for sodium reabsorption. The hormone involved is aldosterone.

EXCRETION OF DRUGS AND DRUG METABOLITES

Many drugs and their metabolites are excreted from the body through the kidneys by the processes of glomerular filtration and secretion. Like other filtered substances, the rate of filtration of drugs will depend on their molecular size and charge. Drugs that bind to plasma proteins are filtered very slowly because of the size of the complex. Some drugs are cleared from the blood purely by glomerular filtration, and thus the rate of clearance cannot exceed the GFR of 125 ml per min, whereas other drugs are excreted by a combination of filtration and secretion, such as benzylpenicillin, which achieves a total clearance rate of 480 ml per min (Shitara et al. 2006; Bennett et al. 2012).

CONCENTRATION AND DILUTION OF URINE

The components of the nephron that are involved in the concentration and dilution of the urine are the loop of Henle and the collecting ducts. The concentration of urine is measured in units of osmolality (mosm per kg water). The most dilute urine that humans can produce is approximately 60 mosm per kg water, but this situation occurs in the pathological condition of diabetes insipidus in which the pituitary gland fails to produce ADH. The most concentrated urine that can be produced is approximately 1400 mosm per kg water, which is greater than four times more concentrated than plasma (plasma osmolality = 285 mosm per kg water) and requires maximum ADH secretion. The average range of urine osmolality in people with normal kidneys is 300–500 mosm per kg water.

REGULATION OF BODY FLUID VOLUME AND OSMOLALITY

Sodium is the main extracellular cation (positively charged ion) and is intimately related to extracellular volume. An increase in body sodium content could lead to an

increase in extracellular fluid volume, leading to hypertension and oedema; and a decrease in body sodium content could lead to a decrease in extracellular fluid volume, leading to hypotension and dehydration. Thus, it is vitally important that body sodium content is kept at a constant level if body fluid volume is to remain constant. Fortunately, the healthy kidney conserves sodium very efficiently in shortage, and can excrete 10–150 mmol per day when sodium is in excess.

Sodium levels (hence fluid volume) are regulated by three hormones: ADH, aldosterone, and atrial natriuretic peptide.

Antidiuretic hormone

ADH is secreted from the posterior pituitary gland in response to a rise in plasma osmolality. Osmoreceptors in the hypothalamus detect small changes in the plasma osmolality and send signals to the posterior pituitary to secrete more or less ADH. Since sodium, along with its associated anion (negatively charged ion) chloride (Cl^-), contributes approximately 95% of the extracellular fluid osmolality, sodium concentration of extracellular fluid is obviously important in determining ADH secretion.

ADH receptors are found in the collecting ducts of kidney tubules and ADH acts to open water channels found here. If water channels in the walls of the collecting ducts open, water will move out of the collecting duct into the medullary interstitium and finally into the circulation. The fall in plasma osmolality then leads to a slowing down of ADH secretion by negative feedback (Figure 2.8).

Aldosterone

Aldosterone is a steroid hormone secreted from the adrenal cortex. It acts on the distal tubule of the nephron: the more aldosterone is secreted; the more sodium is reabsorbed. Aldosterone, however, is not the sole determinant of body sodium balance, although in extreme cases of oversecretion of aldosterone, such as in Conn's syndrome, hypertension may result from overretention of sodium and water.

The secretion of aldosterone, unlike ADH, is not directly triggered by extracellular osmolality but is regulated by a peptide, angiotensin II. See Figure 2.9.

Atrial natriuretic peptide

This peptide is released from cardiac atrial cells in response to an increased atrial stretch. It has five known major effects:

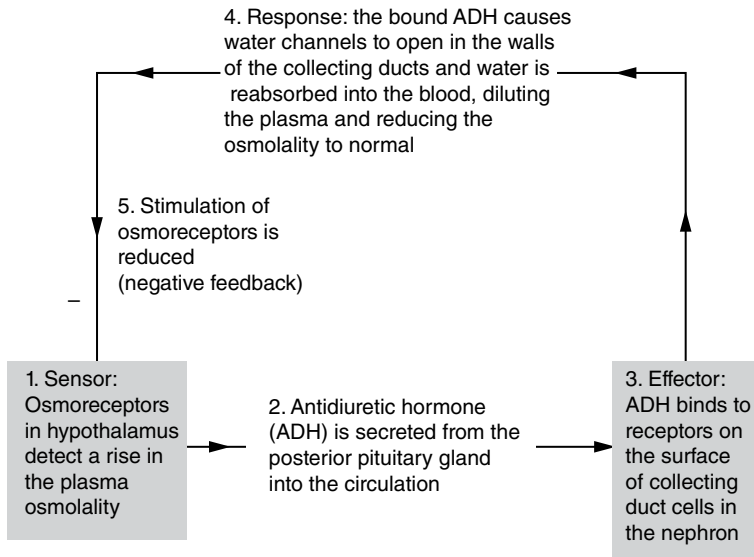


FIGURE 2.8 Negative-feedback loop for antidiuretic hormone (ADH) release and control of plasma osmolality.

1. inhibition of aldosterone secretion by the adrenal cortex;
2. reduction of renin release by the kidney;
3. reduction of ADH release from the posterior pituitary;
4. vasodilation;
5. natriuresis and diuresis.

All of these effects result in the excretion of sodium and water through the kidney, reducing the extracellular fluid volume back to normal. Other factors which may be important in sodium regulation are renal prostaglandins, kinins, and the renal nerves. Failure to regulate the extracellular fluid volume occurs commonly in people with kidney disease and leads to hypertension.

THE RENIN-ANGIOTENSIN-ALDOSTERONE PATHWAY

The distal convoluted tubule forms a unique contact with the glomerulus, passing in the angle between the afferent and efferent arterioles. At this point, specialised cells called the *macula densa* in the wall of the distal tubule make contact with cells in the endothelium of the arterioles, which release a hormone called *renin*. The macula densa and the renin-releasing cells are collectively called the *juxtaglomerular apparatus* or complex (see Figure 2.5).

The juxtaglomerular apparatus is responsible for maintaining a constant blood flow through the glomerulus,

and thus a constant GFR despite fluctuations in arterial pressure. This is achieved through a tubule feedback mechanism in which a fall in GFR results in a fall in the chloride ion concentration in the distal tubule. This stimulates the macula densa cells, which send signals to the renin-secreting cells to release renin. Renin acts via the renin-angiotensin system (Figure 2.9) to produce both local vasoconstriction of the efferent arteriole (increasing GFR) and peripheral vasoconstriction to increase arterial blood pressure. In addition, salt and water retention increase due to the effects of aldosterone.

ALDOSTERONE AND THE CONTROL OF BODY POTASSIUM CONTENT

Potassium is the main intracellular cation. Only about 2% of the total body potassium content is extracellular. Potassium ions are freely filtered at the glomerulus: 65% of reabsorption takes place in the proximal tubule. However, the renal handling of potassium ions is not as efficient as that of sodium, nor is potassium conserved so well when there is a shortage. The secretion of potassium is also linked to that of sodium and hydrogen ions. Unlike sodium regulation, where aldosterone is just one factor in the regulation of sodium content, aldosterone is the only hormone involved in the control of potassium content and thus has a very important regulatory role. Small increases in extracellular potassium concentration directly stimulate aldosterone secretion from the adrenal cortex. The effect of aldosterone in the distal tubule of the nephron is to increase the secretion of potassium into the urine. When aldosterone levels fall, the reverse occurs, and less potassium is secreted.

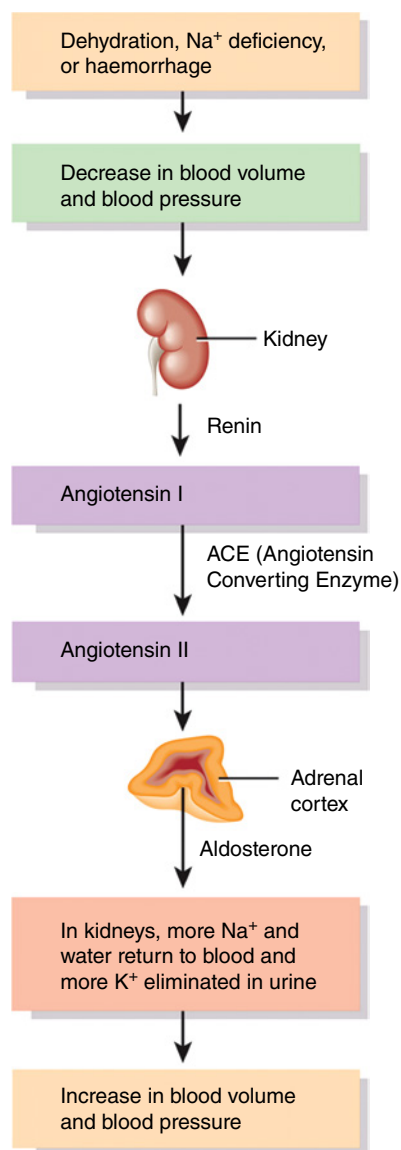


FIGURE 2.9 The renin–angiotensin–aldosterone pathway.
 Source: Tortora and Derrickson (2007). This material is reproduced with permission of John Wiley & Sons, Inc.

The release of aldosterone stimulated by rises in extracellular potassium concentration is strongly controlled by a negative-feedback system. Once the potassium concentration returns to normal, the stimulus to secrete aldosterone is quickly switched off.

The hormone aldosterone increases sodium reabsorption in exchange for potassium or hydrogen ions. If excess potassium ions need to be secreted, then fewer hydrogen ions can be secreted and vice versa. Clinically, this phenomenon results in an association between

metabolic acidosis and hyperkalaemia (or conversely, metabolic alkalosis and hypokalaemia), because in patients with acidosis the distal tubules will increase the rate of hydrogen ion secretion (to prevent a fall in plasma pH) by reducing the rate of potassium ion secretion, resulting in the retention of potassium ions in the blood, leading to hyperkalaemia.

HYPOKALAEMIA AND HYPERKALAEMIA

Potassium, K⁺ (normal range 3.5–5 mmol per litre), is the principal electrolyte of the intracellular fluid, with only low concentrations (2%) circulating in the extracellular fluid. Potassium is provided by the diet and excreted mainly by the kidneys, where regulation of the body potassium content occurs – a small amount is also lost in the faeces. Potassium is necessary to maintain nerve conduction and plays a major role in control of cardiac output. Disturbances in potassium balance show their effects in the electrocardiogram (ECG) and abnormal nerve and muscle function.

Potassium levels usually remain normal if a urine output in excess of 1500 ml per day can be maintained. Hypokalaemia (<3.5 mmol per litre) may be found in cases of diarrhoea, vomiting, renal tubular acidosis, diuretic usage, intravenous fluid administration without added potassium, and when excess insulin causes an increase in the cellular uptake of potassium. Hypokalaemia can cause cardiac arrhythmias.

Hyperkalaemia (>5.5 mmol per litre but sometimes defined as >6.0 mmol per litre for those on haemodialysis) may be seen in advanced kidney disease, burns, insulin deficiency, post-traumatic conditions (including surgery), disseminated intravascular coagulation, or when potassium-sparing diuretics (e.g. spironolactone) or potassium supplementation (e.g. Slow K) are used, and in any condition where cell damage has occurred causing leakage of intracellular potassium into the extracellular fluid. In CKD, a potassium level >6.5 mmol per litre may be a medical emergency requiring immediate instigation of dialysis or other treatments. If left untreated, it may result in cardiac arrest caused by the arrhythmic effect of potassium build-up. Blood samples for accurate potassium analysis should be delivered swiftly to the laboratory or, if this is impossible, separated and stored, to prevent leaching of intracellular potassium into the serum, which results in a falsely raised level.

Treatment of hypokalaemia by the administration of a potassium salt must be undertaken with care since this may result in hyperkalaemia. The uptake of potassium into cells is also dependent on the acid–base balance in the

patient. Acidosis (low blood pH) causes the release of potassium from cells so acid–base disturbances must first be corrected.

REGULATION OF CALCIUM, PHOSPHATE, AND MAGNESIUM

Calcium and phosphate are the main mineral constituents of bone and thus most calcium and phosphate in the body is found in the skeleton. However, small amounts of both these ions are found in extracellular fluid. Calcium exists in the plasma in two forms. Approximately 50% exists in the free ionised form (1.25 mmol per litre), and the other 50% in a bound form, mainly bound to protein, particularly albumin (1.25 mmol per litre). Usually when serum calcium levels are measured, the total calcium concentration is measured (2.5 mmol per litre). This total calcium is then ‘corrected’ depending on the blood albumin level, since it is the ionised form of the calcium that is important in the extracellular fluid in controlling nerve and muscle conduction. Any condition that leads to a fall in the ionised calcium concentration (even if total calcium remains normal) will lead to the classic symptoms of hypocalcaemia – tetany, muscle cramps, and even convulsions. In situations of hypercalcaemia, the main effects seen are pruritus, extra-skeletal calcification, renal calculi, peptic ulceration, and changes in mental function such as memory loss and depression.

Inorganic phosphate (i.e. those ions carrying a charge) exists in several forms – ‘acid’ phosphate (H_2PO_4^-) and ‘alkaline’ phosphate (H_2PO_4^-). The normal plasma range of total inorganic phosphate is 0.87–1.45 mmol per litre. Phosphate is important in buffer systems to maintain the plasma pH and exists in equilibrium with calcium.

Both calcium and phosphate are freely filtered at the glomerulus. When the plasma phosphate level is below 1 mmol per litre, all the filtered phosphate is reabsorbed in the early proximal tubule. However, once the plasma phosphate level rises above 1 mmol per litre, the amount of phosphate excreted in the urine rises in proportion to the plasma concentration. Further excretion of phosphate in the distal tubule (by secretion) can occur in response to the rise in the circulating level of PTH. Calcium reabsorption is very similar to that of sodium, in that approximately 65% occurs in the proximal tubule and a further 20–25% in the ascending limb of the loop of Henle, leaving around 10–12% of filtered calcium being delivered to the distal tubule. How much more calcium is reabsorbed in the distal tubule depends on the levels of circulating PTH.

Magnesium is an important intracellular cation involved in energy storage and production. In all, 55% of total body magnesium is found within bones, so it is not surprising that magnesium balance is linked to that of calcium.

PTH increases tubular reabsorption of magnesium. Under normal circumstances, gastrointestinal absorption and urinary excretion of magnesium are equal. Gastrointestinal disorders may therefore decrease magnesium uptake, but this is matched by a decrease in renal excretion. Most diuretics and alcohol increase renal magnesium excretion.

RENAL HANDLING OF CALCIUM AND PHOSPHATE – THE ROLES OF PTH, VITAMIN D, AND CALCITONIN

The mechanisms by which plasma calcium and phosphate are regulated are closely interrelated. The two major regulators are PTH and vitamin D. Calcium and phosphate can enter the plasma from the gut and from the bone. Indeed, almost all of the approximately 1 kg of calcium in a 70 kg person is found in the bone. Of this, a few grams exchange daily with the plasma calcium pool. Calcium and phosphate can leave the plasma by being redeposited in bone or by renal excretion.

PTH is secreted by the parathyroid glands situated next to the thyroid. Secretion is stimulated by a decrease in plasma calcium concentration, and reduced when plasma calcium levels rise. Its effect is to raise plasma calcium concentration, mainly by increasing bone breakdown (resorption) and releasing calcium ions. PTH also acts in the kidney, stimulating one step in the conversion of vitamin D to its active metabolite, calcitriol, or 1,25-dihydroxycholecalciferol, also known as 1,25-hydroxyvitamin D.

Vitamin D is a steroid that enters the body either through dietary intake or by the effect of sunlight on the skin. However, this is an inactive form of the vitamin called cholecalciferol. To become activated it needs to undergo two metabolic conversions, one in the liver and one in the kidney. These conversions result in the formation of calcitriol. This active form has its effect in the gut, kidney, and (in the presence of PTH) on bone, raising plasma calcium levels. The actions of vitamin D are summarised in Figure 2.10.

The effects of both vitamin D and PTH are to increase the plasma calcium concentration. However, these effects are carefully controlled by a negative-feedback system that prevents the calcium level rising too high. The negative-feedback system is outlined in Figure 2.11. Only if calcium levels suddenly rise high (as after a high-calcium meal) is

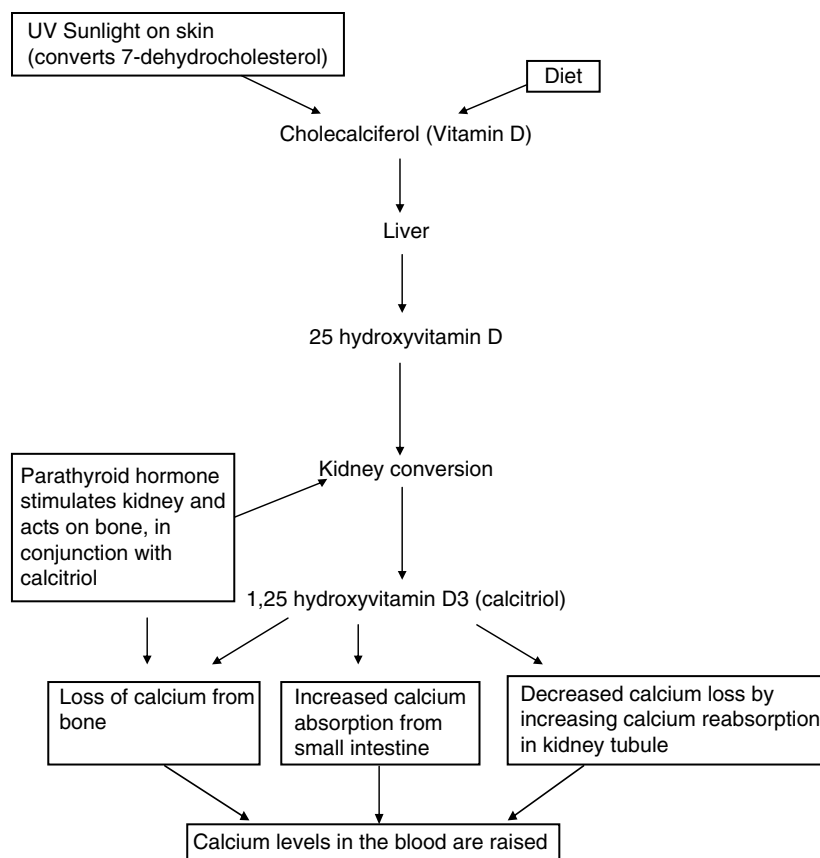


FIGURE 2.10 The actions of sunlight, vitamin D, and parathyroid hormone (PTH) on blood calcium.

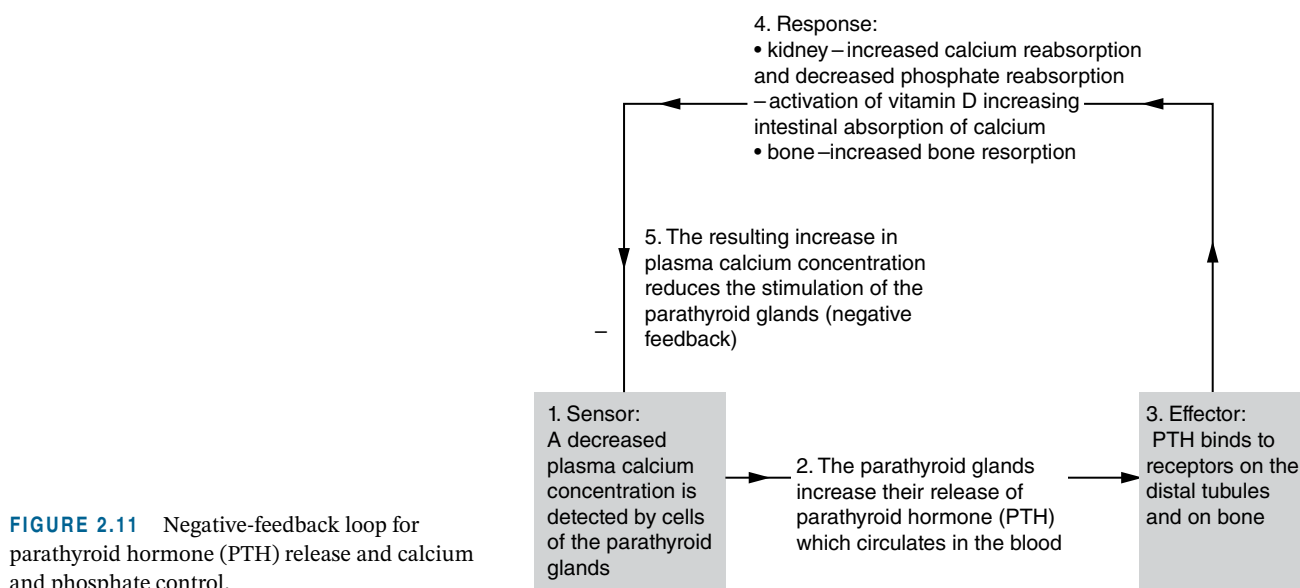


FIGURE 2.11 Negative-feedback loop for parathyroid hormone (PTH) release and calcium and phosphate control.

calcitonin stimulated to be released from the C cells of the thyroid gland, causing calcium to be redeposited in the bone. This is a rapid and relatively short-acting effect. The control of calcium and phosphate levels is essential for the maintenance of normal bone. In renal disease the production of calcitriol is reduced, thus removing the negative-feedback effect on PTH. The result is a rise in PTH leading to loss of calcium from bone and the complications of renal bone disease. Renal bone disease is discussed in Chapter 7.

Calcium ions play an important role in the regulation of nerve and muscle function and in blood clotting. Hypocalcaemia is characterised by increased excitability of muscles leading to tetany, when skeletal muscles go into spasm. Hypercalcaemia is a common finding in an individual with renal failure.

ACID-BASE CONTROL

Acid-base balance is about maintaining the constancy of the pH of the body's fluids. The pH scale is a logarithmic scale (range 1–14) that measures the concentration of free hydrogen ions in a fluid. In fact, the scale is reciprocal, which means that as the pH becomes lower, the hydrogen ion concentration gets increasingly greater. Thus, at acidic pHs (below 7), the hydrogen ion concentration of the fluid is very high relative to that at basic pHs (above 7). In fact, for each point on the scale there is a 10-fold difference in the hydrogen ion concentration. When we consider that the normal pH range of our bodily fluids is between 7.35 and 7.45, this appears very narrow but represents over a 20% difference in the hydrogen ion concentration! It is doubtful we would tolerate a 20% change in our sodium ion concentration with such ease.

Acids are molecules that in the right environmental conditions will give up or donate a hydrogen ion to the solution they are in, and a base is a molecule that mops up or accepts free hydrogen ions from the solution. Thus, to maintain a constant hydrogen ion concentration (and hence constant pH), both acids and bases need to be present in the solution to donate or accept free hydrogen ions as required. Acids and bases working together in this way to minimise changes in pH are called buffers.

Though there are several buffering systems in the body, including haemoglobin, plasma proteins, organic, and inorganic phosphates, the most important one physiologically is the bicarbonate buffering system.

BICARBONATE BUFFERING SYSTEM

To understand the bicarbonate buffering system, the following reaction sequence needs to be understood:



This equation explains how the components of the buffering system are generated in the plasma. Carbon dioxide is generated by cells as an end-product of metabolism and diffuses into the plasma. The CO_2 dissolves in water to form carbonic acid (H_2CO_3), which is the acid component of the buffering system. The carbonic acid, in turn, is in equilibrium with the hydrogen (H^+) and bicarbonate ions (HCO_3^-). This forms the basic component of the buffering system. This reaction sequence can run in either direction; thus, if there is a build-up of CO_2 in the plasma, then more carbonic acid will be formed and the reaction will be driven to the right in order that more bicarbonate ions can be formed to minimise changes in the pH. However, if an excess of hydrogen ions builds up (from metabolic processes), then the reaction will be driven to the left, resulting in CO_2 and water forming. The excess CO_2 can then be blown off in the lungs. Since this reaction sequence constantly runs backwards and forwards to maintain a constant pH, it follows that pH must be dependent on the relative proportions of CO_2 to bicarbonate ions. This can be shown in the following equation:

$$\text{pH} \propto \text{HCO}_3^- / \text{PCO}_2$$

Both components of this equation can be controlled by the body. The bicarbonate ion concentration is carefully controlled by the kidneys, whereas the PCO_2 is controlled by the lungs. Thus, the lungs and the kidneys are the two main organs that together control the acid-base balance of the body.

CONTROL OF BICARBONATE ION CONCENTRATION BY THE KIDNEY

Bicarbonate ions are freely filtered in the glomerulus. When the plasma bicarbonate concentration is normal (25 mmol per litre), then all the filtered bicarbonate is reabsorbed: 90% reabsorption occurs in the proximal tubule and 10% in the distal tubule. However, if plasma bicarbonate concentration is higher than normal, then this excess bicarbonate is lost in the urine.

The reabsorption of bicarbonate ions in the nephron involves various chemical reactions inside the tubular wall cells. The filtered bicarbonate in the tubule undergoes the whole reaction sequence identified above for the bicarbonate buffering system so that CO_2 and water are formed. This is catalysed by the enzyme carbonic anhydrase, which is found in the brush border of the

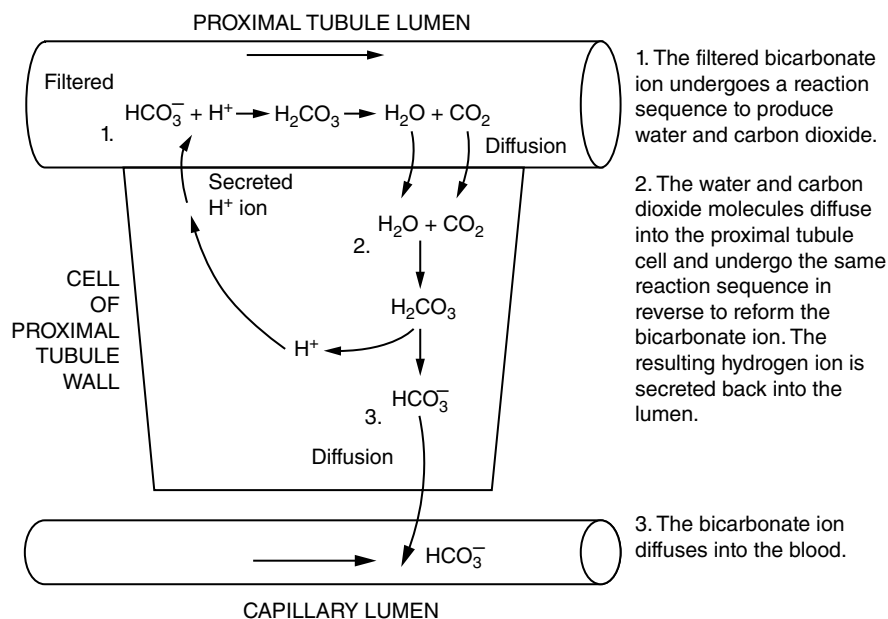


FIGURE 2.12 Bicarbonate reabsorption in the kidney tubules.

proximal tubular cells. The resulting CO_2 then diffuses into the tubular cell, where it undergoes the same reaction sequence, reforming the bicarbonate ion plus a hydrogen ion. The hydrogen ion is secreted into the tubule to be excreted and the bicarbonate ion diffuses into the plasma. This process is sometimes referred to as bicarbonate trapping (Figure 2.12).

This process preserves bicarbonate ions in the blood, but to excrete excess hydrogen ions, substances must take up these ions in the kidney tubule to prevent their reabsorption into the blood. This is the role of the phosphate ions HPO_4^{2-} and the ammonia ions (NH_3), both of which take up one hydrogen ion to form H_2PO_4^- and NH_4^+ , respectively. The process also generates HCO_3^- ions, which can be reabsorbed. NH_4^+ ions cannot readily diffuse back across cell membranes, so the H^+ ions are effectively trapped in the tubule lumen.

The normal range of HCO_3^- is 22–30 mmol per litre. Low plasma HCO_3^- indicates metabolic acidosis caused by CKD with an inability to excrete hydrogen ions adequately.

CORRECTING ACID-BASE FLUCTUATIONS IN THE HEALTHY INDIVIDUAL

Fall in plasma pH

This is a condition called acidaemia or, more commonly, acidosis. This problem arises when there are excess hydrogen ions in the body fluids. In the absence of respiratory or

renal disease, the initial response to control pH is for the excess hydrogen ions to drive the bicarbonate reaction sequence to the left to produce CO_2 and water. The lungs can then deal with this excess CO_2 by increasing the respiratory rate to 'blow off' the CO_2 . This process gives a quick short-term compensation to the problem but not long-term correction. The rise in hydrogen ion concentration is then corrected by the kidneys secreting the excess hydrogen into the urine and in the process generating further bicarbonate for reabsorption into the plasma.

Rise in plasma pH

This condition is called alkalaemia or alkalosis and arises when there is a reduction in the hydrogen ion concentration of the body fluids. The kidney plays the main role in correcting this problem by reducing the amount of hydrogen ion secretion. However, because hydrogen ion secretion and bicarbonate reabsorption are coupled together, this also results in a reduction in the plasma bicarbonate level. The plasma bicarbonate concentration is then corrected by a reduction in ventilation rate by the lungs, which leads to a build-up of CO_2 , which drives the reaction sequence to the right to generate more bicarbonate ions.

Though the above compensatory and correction processes buffer the small fluctuations that occur in the acid-base balance in the healthy individual, larger

BOX 2.3**METABOLIC ACIDOSIS****Causes of acidosis in established kidney disease**

- Reduced renal excretion of acids
- Reduced renal reabsorption of bicarbonate

Markers and symptoms

- Plasma pH falls (as hydrogen ion concentration rises).
- Plasma bicarbonate concentration decreases.
- Anion gap (difference between the plasma concentration of cations Na^+ and K^+ and anions Cl^- and HCO_3^-) increases.
- Possible hyperkalaemia could lead to fatal cardiac arrhythmias.
- Depressed central nervous system could cause coma.
- Respiratory compensation, hyperventilation (Kussmaul's breathing).
- Renal bone disease could develop.

fluctuations in acid–base balance tend to occur when there is either respiratory or metabolic disease. This is because the normal correction mechanisms are blocked. For example, in disorders of ventilation, a respiratory acidosis or, rarely, alkalosis may develop, whereas in disorders of metabolism (including kidney disease) a metabolic acidosis or alkalosis may develop. Box 2.3 for a brief outline of the causes and symptoms of the metabolic acidosis of kidney disease.

ERYTHROPOIETIN PRODUCTION BY THE KIDNEY

The final important role that the kidney has is the production of the hormone erythropoietin. Erythropoietin is a glycoprotein that promotes the proliferation and differentiation of erythrocyte precursors in the bone marrow. Thus, erythropoietin is necessary for the maintenance of a normal red cell count and prevention of anaemia. The erythropoietin-producing cells of the kidney have been identified (in mice) as being intercalated cells of the collecting ducts in cortical nephrons, with peritubular cells apparently being involved in hypoxic conditions (Nagai et al. 2014). Erythropoietin production is stimulated by hypoxia and inhibited when the hypoxia is corrected, thus its production is controlled by the negative-feedback

principle. The kidney is not the only site of erythropoietin production. However, in the presence of severe renal disease, this extrarenal production of erythropoietin is insufficient to maintain the red cell count at normal levels, achieving only one-third to one-half the normal level. Anaemia is therefore a problem in most patients with chronic and advanced kidney disease, although this can be treated with the use of recombinant erythropoietin. See Chapter 6 for nursing management of anaemia in renal disease.

RELATIONSHIP BETWEEN BLOOD PRESSURE AND RENAL FUNCTION

Despite normal fluctuations in the systemic blood pressure, the kidneys are to some extent able to autoregulate the pressure of blood entering the glomerular capillaries. This ensures that the glomerular hydrostatic pressure remains constant and GFR is maintained. In addition, the kidneys are the source of the hormone renin, which has a direct effect on blood pressure via the renin–angiotensin pathway (see Figure 2.9). If the blood pressure entering the glomerulus drops, then more renin is released, resulting in a rise in systemic blood pressure.

If the filtering mechanism of the kidney is impaired by a drop in hydrostatic pressure within the glomeruli or by damage to glomerular tissue, the ability of the kidney to excrete nitrogenous waste products, and to regulate water and electrolytes, may be impaired. This will ultimately result in symptoms associated with kidney failure, including fluid retention, which leads to hypertension.

Conversely, if blood pressure is persistently raised (hypertension), there is a risk of damage to blood vessels throughout the body, but particularly those in the brain (leading to stroke), coronary vessels, and renal vessels. The renal artery (Figure 2.13), or smaller renal arteries, may become narrowed by arteriosclerosis (e.g. renal artery stenosis or renovascular disease). This will lead to impaired renal blood flow, which will stimulate the release of renin, and the cycle of hypertension is worsened. Hypertension may therefore be both the cause and the result of kidney disease.

BLOOD PRESSURE CONTROL

The control of hypertension is the treatment of priority in patients with chronic kidney disease in preventing the progression of kidney failure and cardiovascular complications. Health education pertaining to cessation of smoking and alcohol, healthy eating, and regular exercise for weight control is just as important in patients with chronic kidney disease as in other patients with hypertension.



FIGURE 2.13 Conventional angiogram showing a normal right renal artery. Contrast material has been injected into the renal artery by means of a catheter, seen just to the right of the vertebral column.

CONDITIONS CAUSING CHRONIC AND ADVANCED KIDNEY DISEASE

In this part of the chapter the reader is introduced to some of the common causes of chronic kidney disease and the altered physiology that results from, or may lead to, renal dysfunction. It is not intended as a complete guide to chronic kidney disease but as a starting point for understanding how important the kidneys are and how their function interacts with other body systems.

Chronic kidney disease is a result of several pathological processes causing irreversible damage to kidney tissue. There is a mass destruction of nephrons, so that the kidneys are unable to maintain fluid and electrolyte balance and excrete waste products from the body.

Chronic kidney disease is caused by a slow, progressive decline over a course of many years (perhaps 10–20). There may be an insidious onset of kidney failure with minimum symptoms developing in the patient as they approach to advanced kidney disease. Unlike acute kidney injury, where a full recovery of kidney function can occur, in chronic kidney disease the kidneys are permanently damaged, and the disease is usually progressive. According to the National Kidney Foundation Kidney Disease Quality Outcome Initiative (K-DOQI), chronic kidney disease is diagnosed when tests have persistently (for three months or more) shown a reduction in kidney function (eGFR less than 60 ml per min/1.73m²), or the presence of proteinuria, with an

urinary albumin : creatinine ratio (ACR) persistently greater than 3 mg per mmol (KDIGO 2012). See Chapter 6 for further explanation of stages 1–5 of chronic kidney disease.

The most common causes of advanced kidney disease resulting in renal replacement therapy in the UK are diabetes mellitus, hypertension, glomerulonephritis, pyelonephritis, polycystic kidney disease, and renal vascular disease (UK Renal Registry 2022).

RENAL ARTERY STENOSIS

Renovascular hypertension is high blood pressure due to narrowing of the arteries that carry blood to the kidneys (Marshall et al. 2014). This condition is also called renal artery stenosis. In renal artery stenosis there is a major reduction in kidney perfusion. This alteration results in increased renin secretion and activation of the renin–angiotensin system. If left untreated, accelerated hypertension will develop, resulting in further damage to the kidneys. Conditions causing renal artery stenosis include:

- *Atherosclerosis*. Lipids and fibrous tissue line the main renal artery and its larger branches.
- *Fibromuscular dysplasia*. Narrowing of arteries in the kidney (and other vessels including the carotid arteries). This principally occurs in young women.
- *Hyaline arteriolar sclerosis*. Vessel walls thicken due to the deposition of hyaline material, narrowing the lumen. This occurs naturally after 50 years of age but is also seen earlier in diabetes. Obstruction to the renal blood flow can also be caused by:
 - *Vasculitis*. Necrosis and inflammation of the vessel walls occur because of immunological changes.
 - *Embolism*. The kidney is a common site of embolism from circulating cardiac thrombi.
 - *Thrombosis*. Intravascular coagulation in the arterioles and glomerular capillaries of the kidney, which will result in renal tissue infarction (Figures 2.14–2.15).

Disease progression and prognosis

Hypertension resulting from renal artery stenosis may be treated by drugs to reduce blood pressure or by lipid-lowering treatment. The stenosis itself can be treated by angioplasty of the renal artery with intra-arterial balloon catheters, by insertion of a stent, or by surgical bypass of the narrowed vessel (McLaughlin et al. 2000). A Cochrane review of medical therapy versus balloon angioplasty (with

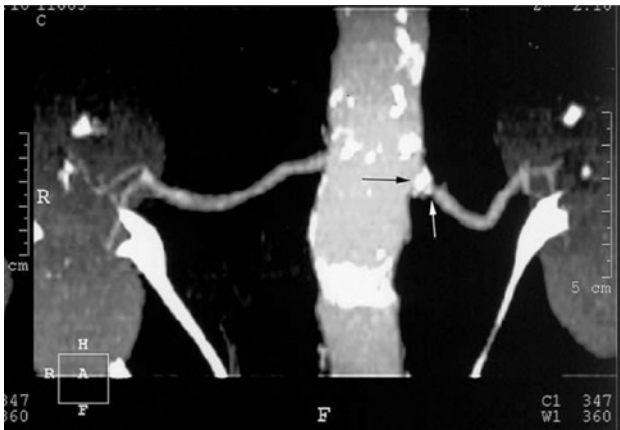


FIGURE 2.14 Computed tomography scan showing left renal artery stenosis. The black arrow points to a calcified plaque at the origin of the artery with narrowing of the artery distal to the plaque (white arrow). Heavy calcification is seen in the aorta (bright patches).

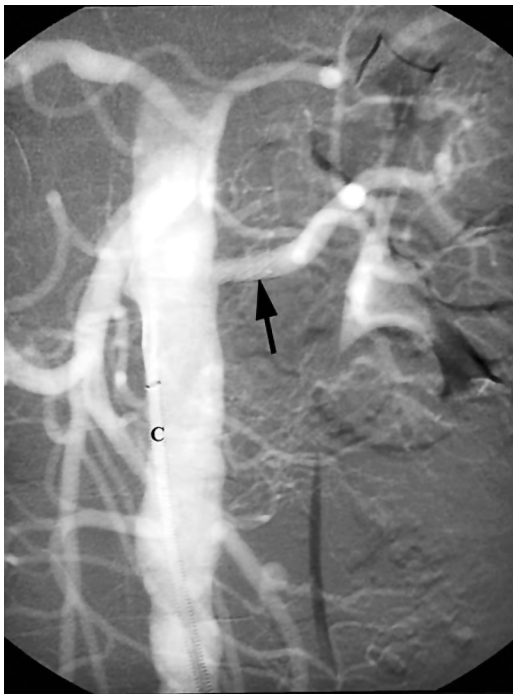


FIGURE 2.15 Digital subtraction angiogram of the same patient shown in Figure 2.14 following treatment by insertion of a metallic stent (black arrow) to improve the blood flow to the left kidney. C, catheter.

or without stenting), carried out in 2014, did not identify significant differences between the treatments (Jenks et al. 2014). The European Society of Cardiology (2017) has produced guidelines on treatment.

NEPHROSCLEROSIS

Hypertension can cause nephrosclerosis and is a major precipitating factor of renal disease. Hypertension that is not treated leads to sclerosis of the renal arterioles, and the blood supply to glomeruli, tubules, and interstitium gradually decreases. Scar tissue develops in the kidney, resulting in loss of renal function and eventually chronic kidney disease.

NEPHROTIC SYNDROME OR NEPHROSIS

The nephrotic syndrome is not a disease but a collection of symptoms. It is characterised by:

- heavy proteinuria (greater than 3.5 g in 24 hours);
- serum albumin <25 g per litre;
- protein:creatinine ratio >350 mg per mmol;
- severe and generalised oedema.

Nephrotic syndrome may develop in a patient with a primary kidney disease of unknown cause (idiopathic nephrotic syndrome) or it may be associated with other conditions in which kidney involvement is secondary, such as amyloidosis or diabetes mellitus (Figure 2.16).

PATHOLOGY OF NEPHROTIC SYNDROME

The nephrotic syndrome is the result of glomerular damage increasing the glomerular basement membrane permeability, allowing large amounts of small albumin molecules to pass through into the urine. It should be remembered that the size of the albumin molecule is

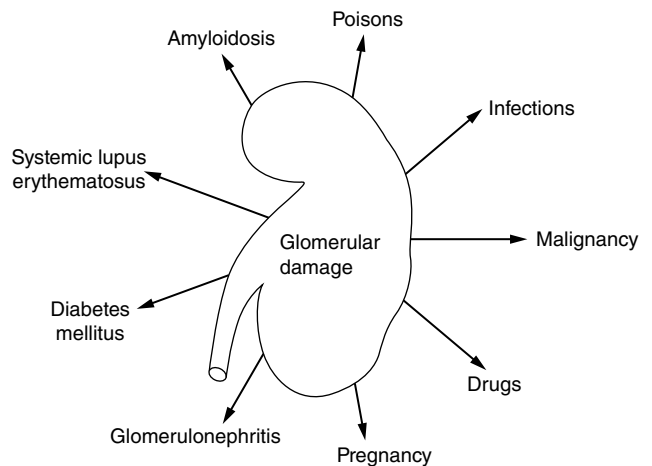


FIGURE 2.16 Causes of the nephrotic syndrome.

just at the cut-off point in size of particle, which may pass through the glomerular filter (see Figure 2.5). As the disease progresses, larger-molecular-weight proteins leak through the glomerular basement membrane and GFR may also reduce as the glomerular damage increases.

As the protein continues to be excreted, the serum albumin decreases (hypoalbuminaemia). This, in turn, leads to a low blood colloid osmotic pressure BCOP and diffusion of fluid into the tissue spaces causing generalised oedema.

A reduction in the circulating blood volume stimulates the release of renin from the kidney, resulting in more aldosterone being released from the adrenal cortex, which is responsible for the retention of sodium and water. Retained fluid also passes out of the capillaries into the tissue, causing more oedema (Figure 2.17).

In the early stages of the nephrotic syndrome, the protein leak may be the only disorder of renal function, but with some glomerular lesions, the disease progresses and nephrons are destroyed. This will lead to established renal failure and the patient will require dialysis.

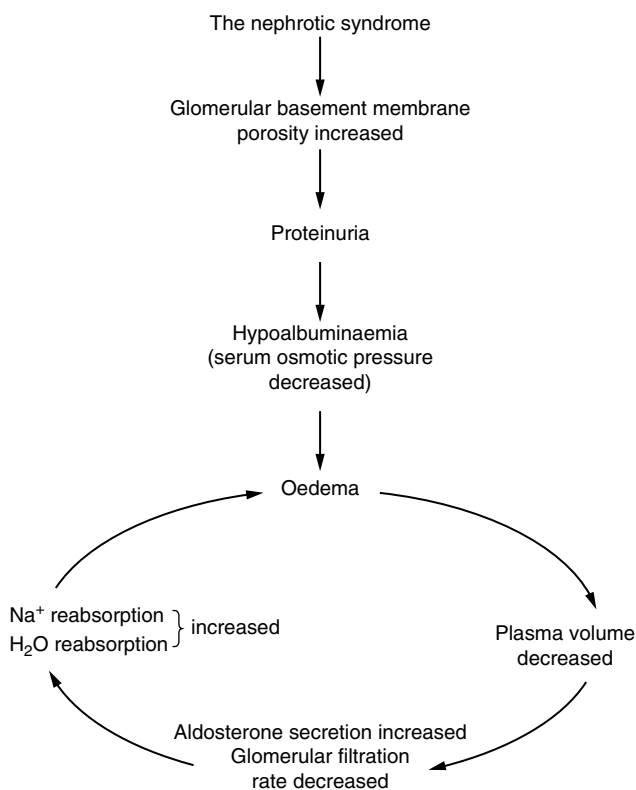


FIGURE 2.17 Oedema formation in the nephrotic syndrome.

CLINICAL FEATURES OF NEPHROTIC SYNDROME

Oedema

In the early stages of the nephrotic syndrome, swollen eyes at the start of the day and swollen feet and ankles at the end of the day may be observed. As the disease progresses, or because of poor symptom control, the oedema becomes more generalised, causing pleural effusions and peritoneal ascites, resulting in breathlessness and abdominal distension.

Fluid removal will be the treatment of priority for patients, but diuretic therapy must be administered carefully because profound hypoalbuminaemia may cause a reduced circulating blood volume, triggering a hypotensive response in some patients following the administration of large doses of intravenous diuretics. Infusions of small volumes of intravenous salt-poor albumin prior to the administration of diuretics will increase plasma volume and restore a diuretic response in the patient. In the majority of patients the albumin is excreted after 24–48 hours.

Proteinuria

Urine has a frothy appearance due to the high protein content (losses greater than 3.5 g in 24 hours), and therefore hypoalbuminaemia develops. The loss of immunoglobulins increases the risk of infection. Hyperlipidaemia is also a clinical sign of the nephrotic syndrome due to the liver synthesising more cholesterol and lipids. This makes the plasma milky in appearance.

Muscle wasting

Muscle wasting is a result of protein mobilisation into the blood to counteract protein lost in the urine.

Weight loss and malnutrition

Chronic nausea, vomiting, and poor appetite may result from congestion in the gastrointestinal tract due to oedema. Weight loss also results from proteinuria and muscle wasting.

Tiredness and lethargy

These symptoms may be attributed to a combination of reduced calorie intake, muscle wasting, and the generalised oedema which may increase body weight by up to 10 kg.

Intravascular clotting

There is a risk of spontaneous intravascular clotting due to the increase in circulating clotting proteins along with venous stasis in the legs and a reduction in plasma volume.

Nephrotic syndrome in children

Nephrotic syndrome in children can lead to frequent infections, hypoproteinaemia, and oedema. The use of corticosteroids has reduced mortality rates to around 3% (Hodson et al. 2007), although some cases are resistant to steroid treatment, in which case other immunosuppressants may be used (Ulinski and Aoun 2012).

DIABETIC KIDNEY DISEASE

Diabetic nephropathy is the term used to describe damage to the kidney structure and function that occurs because of the long-term complications of diabetes mellitus. Type-1 and type-2 diabetes mellitus are characterised by raised blood glucose levels and sustained hyperglycaemia. High glucose concentrations induce specific cellular effects, which affect various kidney cells including endothelial cells, smooth muscle cells, mesangial cells, podocytes, cells of the tubular and collecting duct system, and inflammatory cells and myofibroblasts (Forbes and Cooper 2013).

There is evidence of a heritable susceptibility to developing diabetic nephropathy (Brennan et al. 2013). Glycosylation of proteins occurs, for example glycosylated haemoglobin (HbA_{1c}). These biologically active molecules are known as advanced glycosylation end products or AGEs, and it is thought that these compounds contribute to vascular tissue damage. Patients with diabetes are therefore at increased risk of suffering micro and macro vascular damage resulting in a range of cardiovascular, renal, and other sequelae. Diabetic kidney disease develops in 30–40% of patients with type-2 diabetes and in 2020, diabetic kidney disease remained the most common cause of kidney failure (UK Renal Registry, 2022).

Pathology

Patients initially develop microalbuminuria, i.e. 30–300 mg per 24h. This may not occur for up to 10 years after diagnosis of type-1 diabetes mellitus, but diabetes mellitus may go undetected for so long that microalbuminuria or proteinuria is present at diagnosis of diabetes. After 1–5 years, proteinuria becomes clinical, even to nephrotic levels (>3.5 g per day). With good blood pressure and glycaemic control, and with prescription of ACE inhibitors or angiotensin receptor blockers (ARBs), it is possible to delay the progression from micro to macroalbuminuria and to slow the decline in GFR. The first line of treatment for controlling the progression of diabetic nephropathy is tight glycaemic control, along with the use of angiotensin-converting enzyme inhibitors (ACEI) to control blood pressure (Thomas and Karalliedde 2015)

and sodium-glucose transport protein 2 (SGLT-2) inhibitors such as dapagliflozin.

The kidneys may be of normal size or slightly larger than normal. In type-1 diabetes, the most important structural changes involve the glomerulus, whereas in patients with type-2 diabetes, tubulo-interstitial and vascular lesions are more common (Vestra and Fioretto 2003). There are several pathologies associated with diabetes mellitus:

- Diabetes mellitus is a common cause of pyelonephritis, causing chronic kidney disease and a result of autonomic neuropathy in the bladder.
- Diffuse intercapillary glomerulosclerosis causes thickening and sclerosis of the basement membrane of the glomerular capillary and proliferation of the mesangial cells.
- The glomerulus becomes increasingly replaced and destroyed by the deposition of nodules of a glycoprotein material – nodular glomerulosclerosis (or Kimmelstiel–Wilson nodules).
- Arteriosclerosis develops in the arteries, supplying the glomerulus due to hyaline deposits in the afferent and efferent arterioles, causing ischaemia and accelerating the disease process.
- Papillary necrosis occurs.

GLOMERULONEPHRITIS

The term *glomerulonephritis* covers a group of conditions in which inflammation in the glomerulus occurs, either as a primary disease or as part of a systemic illness. It is therefore important to consider the possibility of an underlying systemic condition if glomerulonephritis is diagnosed. See Cunard and Kelly (2003) for further reading.

Glomerular disease occurs when the structure or function of the glomerular capillary network has been damaged as a result of antigen–antibody reactions in the glomeruli.

There are contributions from lymphocytes, macrophages, antibodies, immune complexes, and inflammatory mediators. The glomerular cells may proliferate, basement membrane thicken, or exudates of leukocytes and platelets build up in the glomerulus. These tissue reactions result in changes in the filtration properties of the glomerulus, leading to proteinuria, haematuria, impaired excretory kidney function, and hypertension.

Any age group may be affected, though some types are particularly common in children. The estimated incidence of glomerulonephritis is 0.2–2.5/100 000 per year, rising to 6.2–15.6/100 000 per year for minimal change

BOX 2.4**GLOMERULAR DISEASE**

Glomerulonephritis is the term used to describe a variety of disorders that principally affect the glomeruli in the kidney. Such glomerulopathies may arise as primary disorders of the glomerulus, or as part of a systemic disorder such as systemic lupus erythematosus (SLE) or diabetes mellitus.

Histopathology

- Glomerular damage may be manifest as one or more of the following tissue reactions:
- Cellular proliferation leads to an increase in the number of cells in the glomerular tufts.
- Leukocyte infiltration of inflammatory cells – mainly neutrophils and monocytes.
- Basement membrane thickening might be a result of diabetes mellitus or a response caused by precipitated immune complexes.
- Hyalinisation and sclerosis. Hyalinisation is the accumulation of homogeneous, amorphous substance in the glomerular tuft composed of mesangial matrix, basement membrane, and plasma protein. Sclerosis is the total obliteration of structural detail in the glomerular tuft and is the end result of glomerular damage.

Clinical manifestations

Clinical presentation of glomerular disease may range from an acute onset of disease with a reversible outcome, to a chronic

insidious onset that eventually leads to renal failure after several decades. A number of syndromes of glomerular disease are defined:

- *Proteinuria* occurs if the glomerular basement membranes are damaged so that they leak protein.
- *Nephrotic syndrome* occurs if the basement membranes are damaged more severely and increase the protein leak to greater than 3.5 g protein 24 h⁻¹. This, in turn, induces a low serum albumin and generalised oedema. Hyperlipidaemia usually also occurs.
- *Haematuria* occurs if capillary walls are disrupted, allowing red cells to pass into the urine. This may be microscopic or macroscopic. However, most forms of haematuria are non-glomerular in origin.
- *Nephritic syndrome* occurs when basement membrane damage and red blood cell leakage are present together, leading to proteinuria and haematuria, accompanied by generalised oedema and mild hypertension.
- *Established renal disease* occurs when damage to the glomeruli is severe enough to impair the normal filtering function of the glomerulus, resulting in an accumulation in the blood of substances such as urea, creatinine, and potassium.

disease in Asian children (McGrogan et al. 2011). See Box 2.4 for histopathology.

The prognosis depends to a large extent on the particular subtype of glomerulonephritis, identified by the pattern of glomerular injury involved.

Subtypes of glomerulonephritis

- minimal-change glomerulonephritis (renal biopsy normal by light microscopy);
- membranous glomerulonephritis;
- mesangial proliferative nephritis;
- focal segmental glomerulosclerosis;
- crescentic glomerulonephritis (associated with syndrome of rapidly progressive glomerulonephritis);
- mesangiocapillary glomerulonephritis (MCGN);
- post-infection glomerulonephritis.

Minimal-change glomerulonephritis

The condition is so named due to the essentially normal appearance of the glomeruli under the light microscope. It most often presents in children aged 2–4 years of age, and accounts for 90% of cases of nephrotic syndrome in children. The condition is very rarely associated with impairment of excretory renal function and is occasionally secondary to drug use (particularly non-steroidal anti-inflammatory drugs [NSAIDs]) or malignancy (e.g. lymphoma).

Severe oedema may be present but without associated hypertension.

Membranous glomerulonephritis

These patients typically present with proteinuria, which may be asymptomatic or severe enough to cause nephrotic syndrome. Microscopic haematuria, hypertension, and/or impaired excretory renal function may also be associated. It is seen in adults rather than in children. Onset is insidious

and the disease develops slowly – over the course of 20 years in some cases.

There is widespread thickening of the capillary wall in the glomerulus (but without proliferation of the cells), which seems to result from the deposition of immune complexes in the kidney. This can occur as a result of drug use (particularly NSAIDs, gold, and penicillamine), secondary to tumours (e.g. carcinoma of bronchus or breast), infection (particularly hepatitis B), or hypothyroidism.

Mesangial proliferative nephritis

This is the most common type of glomerulonephritis worldwide. Patients present with haematuria, sometimes with associated proteinuria, hypertension, and impaired renal excretory function. The immunoglobulin IgA is deposited in the glomerulus, and there is sometimes proliferation of the glomerular cells. The cause of the deposits is not known, but it seems the problem is in the IgA system rather than in the kidney. An associated glomerular change is seen in Henoch–Schönlein purpura, a condition more common in children that is associated with a purpuric rash, joint, and gastrointestinal involvement.

Focal segmental glomerulosclerosis

This condition is named after the areas of scarring which occur in the glomeruli. The sclerotic changes affect some glomeruli but not others (focal) and may affect only parts of each glomerulus (segmental). The patient will typically present with nephrotic syndrome (hypertension, haematuria, impaired excretory renal function). Focal segmental glomerulosclerosis can be either primary (idiopathic), meaning there is no identifiable cause, or secondary, meaning it is caused by another condition or drug, such as HIV.

Crescentic glomerulonephritis

Also known as rapidly progressive glomerulonephritis, this condition is associated with rapid but progressive deterioration in kidney function and the presence of oliguria or anuria. Haematuria and proteinuria also occur. In Goodpasture's syndrome, auto-antibodies are directed against collagen – a major structural component of the glomerular basement membrane. Up to half of those with Goodpasture's disease also have pulmonary haemorrhage. Without effective treatment, established kidney failure will develop in weeks and months, rather than years.

Acute inflammation in the glomerulus is the underlying cause, sometimes with the formation of crescents when the glomerulus is squashed by cells which fill the Bowman's space. In some cases, antibodies to the glomerular basement

membrane are present but, in most cases, no immunoglobulin is identified in the glomerulus.

Mesangiocapillary or membrane-proliferative glomerulonephritis

Three subtypes of this condition are recognised, identifiable only by electron microscopy. In all cases the presentation of the patient is similar, with proteinuria, haematuria, hypertension, and impaired renal function. There are no known causes. All types tend to have a progressive course, and up to 50% of patients develop chronic kidney disease within 10 years.

Post-infection glomerulonephritis

Post-streptococcal glomerulonephritis (e.g. following a throat infection) was a common cause of kidney failure in the pre-antibiotic era and is still common in some parts of the world. Immune complexes that arise following infection with group A haemolytic streptococci deposit in the glomerular capillary wall, resulting in proteinuria, haematuria, and hypertension.

Glomerulonephritis may complicate infection with a range of organisms. Infection with *Staphylococcus*, influenza B, hepatitis B and C, and human immuno-deficiency virus (HIV) may all result in kidney damage.

PYELONEPHRITIS

This is a bacterial infection of kidney tissue, with the infection beginning in the lower urinary tract and ascending to the kidney(s). Acute pyelonephritis is commonly associated with pregnancy, obstruction, instrumentation, or trauma to the urinary tract and in patients with a chronic illness.

Chronic pyelonephritis is the result of repeated infections of the urinary tract. There is widespread destruction of nephrons and replacement with scar tissue, which eventually causes established kidney failure. For most patients, the disease starts in early childhood and is due to ureteric reflux and infection, but symptoms of the disease may not present clinically until adulthood. In adults, chronic pyelonephritis is a complication of obstruction in the renal tract, because stone formation and structural abnormalities both cause stasis of urine. Patients present with pyrexia and rigors and loin pain over the affected kidney(s). Symptoms of a lower urinary tract infection may also be present.

REFLUX NEPHROPATHY

Reflux nephropathy is a congenital anatomical abnormality where there is incompetence of the sphincter at the junction of the ureter with the bladder, allowing the reflux

of urine back up the ureter and into the renal pelvis. Infection may develop and the formation of scar tissue will eventually cause chronic kidney disease. If identified early, surgical correction will be needed. Recurrent urinary tract infection during childhood should always be fully investigated and treated.

POLYCYSTIC KIDNEY DISEASE

Polycystic kidney disease is one of several cystic diseases of the kidney. Polycystic disease refers to two hereditary cystic diseases: autosomal recessive polycystic kidney disease (ARPKD) and autosomal dominant polycystic kidney disease (ADPKD). Both conditions may occur in children, although the recessive disease is more commonly seen in this age group. The following descriptions will refer to ADPKD, one of the most common genetic disorders, which is responsible for approximately 10% of patients with kidney failure.

Genetics

The autosomal dominant form of the disease is one of the most common genetic disorders, affecting an estimated 1:400–1000 of the population. The condition occurs equally in men and women and is transmitted by both sexes. Whilst most patients have an affected parent, 10% of cases can be traced to a *de novo* mutation (Harris and Torres, 2014). Symptoms may not develop until patients reach their twenties; the mean age of starting dialysis treatment is 57 years. However, by the age of 80, virtually all individuals who carry the gene will manifest some form of the disease. Mutations in either of two genes PKD1 or PKD2, which code for proteins polycystin-1 and 2, are responsible for the condition (Calvet and Grantham 2001).

ARPKD is a severe, inherited disorder of the kidney that typically presents in the neonatal period with an incidence of approximately 1/20 000. Most affected children die within the first few hours of life, although a number of patients present in later childhood, or as adults. To date, only one gene (PKHD1) has been identified in the inheritance of ARPKD, although there is evidence for locus heterogeneity, making interpretation of genetic screening complex (Bergmann 2015).

Pathology

Both kidneys are considerably enlarged and consist of a compact mass of cysts, which are scattered equally throughout the cortex and medulla (Figure 2.20). The cysts increase in size and eventually rupture, allowing infection and scar tissue formation and reducing the number of functioning

nephrons. The enlarged cysts compress the normal renal tissue and hypertensive changes and glomerulosclerosis occur. Cysts are filled with watery fluid that may be clear, blood-stained from a recent haemorrhage, brown from an old haemorrhage, or filled with pus (Figures 2.18–2.20).

Liver cysts may be found in patients with polycystic kidneys, and there is also a significant association with aneurysms of the cerebral arteries.

Clinical features and management of care

Pain. The patient may complain of abdominal distension or discomfort following minor physical trauma and this may cause frank or microscopic haematuria. Pain in the



FIGURE 2.18 Ultrasound of a normal right kidney.

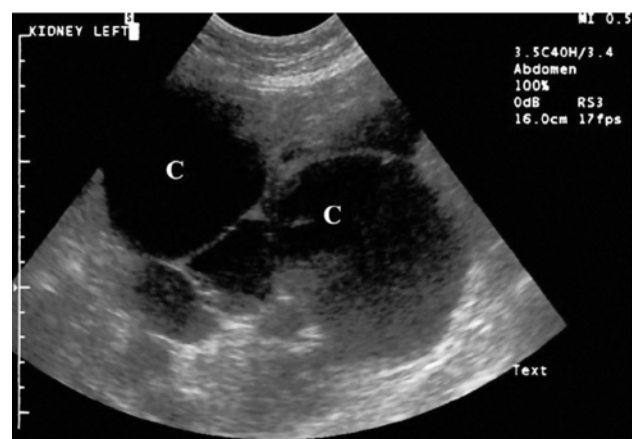


FIGURE 2.19 Ultrasound of a polycystic kidney showing how the normal tissue is replaced by multiple fluid-filled cysts (C).

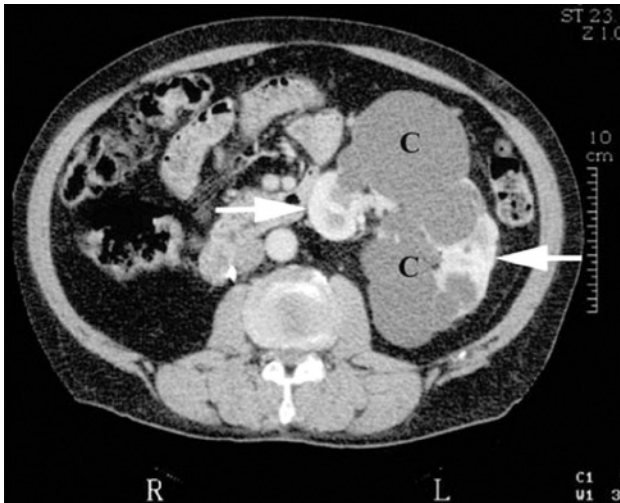


FIGURE 2.20 Computed tomography scan showing a polycystic left kidney; the cysts are marked by C. The white arrows point to normal renal tissue. The right kidney has been removed.

flank is associated with the large cysts rupturing and any blood clots that are passed will cause the patient to experience colic.

- **Haematuria and proteinuria.** Microscopic or frank haematuria is seen in more than 50% of patients. Chronic blood loss does not usually result in anaemia because the erythropoietin production by the kidneys is increased.
- **Urinary tract infections.** Repeated urinary tract infections are common complications and may affect the cysts.
- **Hypertension.** Secondary hypertension is common in patients with polycystic disease and may deteriorate as established renal failure approaches.

MULTISYSTEM DISEASES AFFECTING THE KIDNEY

The kidney may be affected in many ways by disease processes that are not directly associated with renal function. This vulnerability is, in part, due to the high blood supply of the kidneys; together, the kidneys receive 25% of the cardiac output. The glomerular capillaries, because of their filtering properties, come into close contact with all blood constituents.

The effects of diabetes mellitus and of systemic infections in the kidney have already been mentioned. The following are some more examples of multisystem diseases that may affect the kidney.

Systemic lupus erythematosus

This is an autoimmune inflammatory disease that affects joints, blood vessels, skin, and the nervous system, as well as the kidneys. Glomerular inflammation may result in proteinuria, haematuria, and hypertension; renal involvement often occurs within 3 years of diagnosis of the disease. Non-renal manifestations of the disease are usually present, such as arthralgia, rash, and haematological disorders. It can be treated using immunosuppressants and steroids (Bertsias et al. 2012)

Renal amyloidosis

Amyloidosis is the term given to a group of chronic infiltrative disorders characterised by the presence of deposits of an abnormal protein called amyloid. Two groups of protein deposit exist – AL amyloid or AA amyloid – but renal involvement occurs with both. AA amyloid deposits are a complication of many chronic inflammatory diseases, occurring in up to 10% of patients with rheumatoid arthritis; AL amyloid deposits may occur secondary to myeloma or as the primary condition, AL amyloidosis. This is a systemic disease that affects the heart, peripheral nervous system, liver, and kidney. AL accounts for up to 86% of renal amyloidosis cases (Kidd and Carl, 2016).

A common site of deposition of the insoluble amyloid fibrils is in the walls of the renal arterioles and glomerular capillaries. The result is usually nephrotic syndrome followed by progressive renal failure. Ten-year individual survival rate is about 20% (Sasatomi et al. 2007).

Scleroderma or systemic sclerosis

This is a multisystem condition that causes gradual hardening and tightening of the skin and increased binding to subcutaneous tissue. Renal involvement is one of the less common but most serious complications of the disease and, in the past, was a major cause of mortality. Patients often present with the features of malignant hypertension and rapidly deteriorating renal function. Diastolic pressure may exceed 130 mmHg. Antihypertensives, particularly ACE inhibitors, improve the renal outlook of these patients, but there is no treatment for the underlying condition.

Polyarteritis nodosa

More common in men than women, this condition usually presents in later life. It is characterised by widespread inflammation of small and medium arteries and aneurysm formation. Thrombosis in these arteries can lead to complications that particularly affect the gut, peripheral nervous system, and kidneys. The renal presentation is that of

progressive renal impairment caused by renal infarction and hypertension. Treatment is with corticosteroids, and renal prognosis depends on early diagnosis and treatment since organ damage is irreversible.

BIOCHEMICAL BLOOD INVESTIGATIONS IN KIDNEY DISEASE

Normal values for blood tests are listed in Table 2.2. These may vary locally and may be expressed in alternative units of measurement. Paediatric normal values should always be checked (see Chapter 12). Monitoring the blood biochemistry of patients with CKD is central to their diagnosis and ongoing care as this reflects the kidneys’ function in excreting the waste products of metabolism. Serum or heparinised plasma samples are suitable for most biochemistry investigations.

The following tests (urea, creatinine, sodium, potassium, corrected calcium, phosphate, bicarbonate, and albumin) are often requested together. The result is generated from one 5 ml blood sample in a plain or lithium heparin tube. Some centres may include other tests under this profile.

UREA

Urea (normal range 2.5–6.4 mmol per litre) is one of the principal end-products of protein metabolism. Urea is formed in the liver, carried by the blood, and excreted by the kidneys in the urine. Raised blood urea indicates failure of the kidneys and usually increases in tandem with serum creatinine levels in CKD and ESKD. However, serum urea

levels may remain within normal limits whilst serum creatinine levels increase.

Urea can rise dramatically in previously healthy individuals who experience overwhelming infection or major crush injuries and are admitted to hospital with AKI. A slight rise in urea may be seen if a very-high-protein diet is consumed, and in low-protein diets a lower level of blood urea may be observed. Certain drugs, such as corticosteroids and tetracycline, can cause a sudden rise in blood urea, especially if the patient already has CKD.

Nonrenal causes of increased urea levels

- High-protein diet.
- Chronic malnutrition – protein metabolism increases.
- Gastrointestinal bleeds – protein absorption increases.
- Dehydration – urea reabsorption increases.

A normal or low urea level is not necessarily indicative of adequate dialysis if a patient is malnourished with a low protein intake.

CREATININE

Creatinine (normal range 70–120 µmol per litre) is produced by the breakdown of creatine phosphate in muscle by catabolism and is excreted by the kidney. Patients should not eat cooked meat at least 12 hours prior to a serum creatinine test. Creatinine levels may not show a significant increase until there is a 50% loss of kidney function. Therefore, serum creatinine is not a sensitive test for early kidney disease. A higher level of serum creatinine may be expected with large muscle mass, in males, and in those of African-Caribbean ethnicity (see Chapter 6 for use of a correction factor for people of African-Caribbean descent). A lower level may be seen in those with a low muscle mass (e.g. the elderly, those with an amputation, and women), hyperthyroidism, those who are malnourished, and/or with the use of some drugs such as trimethoprim, testosterone therapy, corticosteroids, and vitamin D metabolites and amiloride.

In advanced kidney disease, creatinine levels may eventually rise to a level where it is considered expedient to commence dialysis. This may be in the region of 500–1000 µmol per litre but varies with the individual and the symptoms experienced.

SODIUM

Sodium, Na⁺ (normal range 135–147 mmol per litre), is the principal electrolyte of the extracellular fluid of the blood,

Table 2.2 Analysis of a normal blood sample.

Urea (blood urea nitrogen)	Adult 2.5–6.4 mmol per litre Child 1.1–6.4 mmol per litre
Creatinine	Adult 70–120 µmol per litre Child (increasing with age) 27–88 µmol per litre
Sodium	135–147 mmol per litre
Potassium	3.5–5 mmol per litre
Calcium	2.2–2.65 mmol per litre
Phosphate	0.8–1.5 mmol per litre
Bicarbonate	22–30 mmol per litre
Cholesterol	3.5–5.2 mmol per litre
Total protein	60–80 g per litre
Albumin	35–55 g per litre
Glucose (fasting)	3.9–5.5 mmol per litre

maintaining osmotic pressure, and is involved in acid–base balance and the transmission of nerve impulses. Sodium is taken into the body with the diet and is conserved or excreted by the kidneys. Hyponatraemia (<135 mmol per litre) can be an indication of excess body fluid, and is also often present in burns, diarrhoea, vomiting, nephritis, neoplasms, and diabetic acidosis.

Hypernatraemia (>148 mmol per litre) can be an indication of dehydration and insufficient water intake, multiple myeloma, diabetes insipidus, metabolic acidosis, or excessive intravenous isotonic fluids in advanced kidney disease. Patients may be proportionally hypernatraemic or hyponatraemic without an altered fluid state.

POTASSIUM

See section on hypokalaemia and hyperkalaemia on page 24.

MINERAL AND BONE DISORDER TESTS

Calcium, phosphate, alkaline phosphatase (ALP), parathyroid hormone (PTH), and calcidol (25 (OH)D₃) are routinely monitored in people with CKD or undergoing dialysis.

CALCIUM

Calcium, Ca²⁺ (normal range total Ca²⁺ 2.2–2.6 mmol per litre) is provided by the diet, and is excreted by the kidneys. Most body calcium is found in the skeleton, but a small proportion is circulated in the blood. About 50% of serum calcium is protein-bound and 50% is ionised. Ionised serum calcium is responsible for muscle contraction, cardiac function, and blood clotting. Corrected calcium estimates the total concentration of calcium as if the albumin concentration was normal, i.e. estimates the free calcium, and is calculated as follows:

$$\begin{aligned} &\text{Corrected calcium (mmol/l)} \\ &= \text{Ca}^{2+} + \left(40 - \text{albumin (g/l)}\right) \times 0.02. \end{aligned}$$

It is the corrected calcium value that is reported by the laboratory.

In the healthy individual, calcium homeostasis is controlled by PTH, vitamin D, and the hormone calcitonin. Hypocalcaemia is found in CKD where phosphate retention is present. Chronic hypocalcaemia causes an excess of PTH to be excreted into the bloodstream, which in turn releases calcium from the bone, resulting in the mineral

bone disorder often seen with vitamin D deficiency in CKD. In nephrotic syndrome, low levels of calcium will be found due to albumin leaking into the urine, taking bound calcium with it. In the patient with nephrotic syndrome, the ratio of protein-bound and ionised calcium will remain the same. The acidosis of CKD is an added cause of loss of bone calcium. Hypercalcaemia may be an indication of hyperparathyroidism, sarcoidosis, or malignancy. High levels of calcium can cause kidney stones and renal tubular disease.

PHOSPHATE

Phosphorus is found in the diet. Phosphate, PO₄³⁻ (normal range 0.8–1.5 mmol per litre), is mainly combined with calcium in the skeletal bone. It is controlled, with calcium, by PTH, and apart from its skeletal function has a part in the metabolism of glucose and lipids. Phosphates are excreted by the kidney. When phosphate is increased, calcium is lowered and vice versa.

Hypophosphataemia may be found in the patient with renal tubular disease who loses phosphate, possibly leading to osteomalacia. Hyperphosphataemia will often be found in conjunction with hypocalcaemia.

PARATHYROID HORMONE

Normal values of PTH vary according to the local assay method being used. PTH is a hormone produced in the parathyroid gland and is involved with the regulation of extracellular calcium. This test is useful in establishing whether hypercalcaemia is due to an overactive parathyroid. Increased PTH is common in stage 3 CKD, vitamin D deficiency, and osteomalacia. Hyperparathyroidism has been implicated in reduced response to anaemia treatments and possibly due to the effect on endogenous erythropoietin synthesis, bone marrow progenitors, red cell survival, or as a result of indirectly causing bone marrow fibrosis (NICE 2015). Blood for PTH analysis should be delivered immediately to the laboratory for analysis or, if this is impossible, kept on ice for a maximum of 30 minutes.

CALCITROL (CALCIDOL, 25(OH)D)

The Renal Association (Steddon et al. 2015) has suggested routine monitoring in stages 3–5 CKD and for those patients on dialysis. Calcitrol (normal value: 30–74 ng per ml) is the most active metabolite of vitamin D and is mainly synthesised in the kidneys. Low levels are associated with osteoporosis, CKD, phosphate retention, malabsorption, and obesity (Steddon and Sharples 2015).

OTHER BIOCHEMICAL BLOOD TESTS

Uric acid

Uric acid (normal range female 200–350 μmol per litre, male 260–500 μmol per litre) is an end-product of purine metabolism and is excreted mainly by the kidney, but in part by the bowel. In CKD there is an impaired ability to excrete uric acid, and a high serum level may be found in association with raised urea and creatinine.

Bicarbonate

The normal range of HCO_3^- is 22–30 mmol per litre. Low plasma HCO_3^- indicates metabolic acidosis caused by CKD with an inability to excrete hydrogen ions adequately.

Measuring glucose

The normal range of fasting serum glucose is 3.9–5.5 mmol per litre. Blood glucose levels are maintained by the liver, which absorbs and stores glucose as glycogen and releases it into the circulation in response to the demands of the body.

Glycosylated haemoglobin

Glycosylated haemoglobin, more commonly known as HbA1c, indicates the amount of glucose carried by red blood cells in the body and is a more accurate measure of long-term glucose control in people with diabetes. The target HbA1c in type-2 diabetes is <48 mmol per mol (6.5%), or a higher target if the person is at risk of hypoglycaemia (<53 mmol per mol (7.0%)) (NICE 2017). HbA1c provides an average blood glucose level over a 12-week period (the average life of a red blood cell); however it may underestimate blood glucose control in advanced kidney. Higher results can also be found in uraemia. Other tests may be required to give a more accurate glucose level, which include:

- fructosamine estimation;
- quality controlled blood glucose profiles;
- total glycated haemoglobin estimation of abnormal haemoglobins.

Lipids

Cardiovascular disease is a major cause of morbidity and mortality in patients with kidney disease (Jun et al. 2011) and one of the main risk factors for this is dyslipidaemia. A full lipid profile should include measurement of total cholesterol, HDL cholesterol, non-HDL cholesterol, and triglyceride concentrations. A fasting sample is not needed. A normal value for non-HDL cholesterol is <4 mmol per litre and total cholesterol is ≤ 5.0 mmol per

litre and for those at high risk of cardiovascular disease (CVD) ≤ 4 mmol per litre (NICE 2016). Atorvastatin (20 mg) for the primary or secondary prevention of cardiovascular disease should be offered to people with CKD. The dose should be increased if a greater than 40% reduction in non-HDL cholesterol is not achieved and eGFR is 30 ml per min/1.73m² or more.

Albumin

The normal range of albumin is 35–55 g per litre. Albumin levels can be elevated in patients with dehydration. Low albumin levels are common in CKD due to protein loss through peritoneal dialysate, poor dietary intake, and nephrotic syndrome.

Plasma total protein

The normal range of plasma total proteins is 60–80 g per litre. Hypoproteinaemia associated with low albumin (normal value 35–55 g per litre) levels may be found in the many conditions associated with nephrotic syndrome where protein leakage occurs from the kidney into the urine. Hyperproteinaemia (increase of total plasma protein) with a normal albumin/globulin ratio may occur in dehydration. If total protein increases with a falling albumin/globulin ratio (i.e. a raised globulin), this may indicate autoimmune disease such as systemic lupus erythematosus (SLE), shock, chronic infection, or myeloma.

Serology

Serological tests are frequently required as renal impairment is often a manifestation of a systemic disease. Many kidney disorders arise from immune dysfunction and serology will often, therefore, provide an exact diagnosis. A positive anti-neutrophil cytoplasmic antibody (ANCA) test is found in diseases such as systemic and renal vasculitis. Anti-glomerular basement membrane (anti-GBM) is detected in Goodpasture's syndrome. The presence of other immunoglobulins may indicate other autoimmune diseases (e.g. antinuclear antibodies may be found in SLE).

Complement

The most common complement studies performed are for C3 and C4. These levels rise during an acute inflammatory state.

Creatine kinase

An enzyme present in heart and skeletal muscle, which is elevated in myocardial infarction and rhabdomyolysis.

Immunoglobulins

Immunoglobulins (five groups – IgD, IgE, IgG, IgM, and IgA) are proteins present in both circulating blood and in the cells that function as antibodies defending the body against infection. Elevated levels may be seen in autoimmune disease, cancers, and allergic reactions, for example IgA nephropathy. Cryoglobulins are abnormal immunoglobulins that can be found in autoimmune disease, such as systemic lupus nephritis, and infections such as hepatitis.

Viral serology

Screening for hepatitis B, C, and HIV is required for at-risk groups and those requiring kidney replacement therapy (KRT). HIV and hepatitis B and C can also be a primary cause of kidney disease.

HAEMATOLOGICAL INVESTIGATIONS FOR RENAL ANAEMIA AND OTHER DISORDERS

Haematological tests give information about anaemia, haematological malignancies, and clotting disorders. Infections, inflammatory disease, and other conditions can be indicated by changes in total and differential white cell counts. Normal values are shown in Table 2.3 (there may be slight local variations, especially in the paediatric normal range).

FULL BLOOD COUNT

This test includes haemoglobin, haematocrit, red blood-cell count, white blood-cell count, and differential, platelet count, and blood film, which often provide evidence of renal anaemia in CKD. It may be appropriate to investigate further those values falling outside normal parameters.

HAEMOGLOBIN

Haemoglobin (Hb) should be checked to ensure that anaemia is not present. Haemoglobin varies with age, gender, and ethnicity. The level at which it is considered that an

erythropoietin stimulating agent (ESA) should be initiated varies from one centre to another, but the current recommendation is for an aspirational haemoglobin range of 100–120 g per litre for adults, young people, and children (2 years and older), and investigations for anaemia should be undertaken if Hb < 110 g per litre (NICE 2015). Normocytic erythrocytes are typical in the patient with renal anaemia. However, in the case of iron-deficiency anaemia, microcytic, and hypochromic red blood cells will be seen.

HAEMATOCRIT

Haematocrit (HCT) is the percentage of red blood cells in the whole blood volume, which will be low in the patient with renal anaemia, running in parallel with the low level of haemoglobin. When the patient responds to the effect of erythropoietin, a rise in HCT will be seen in conjunction with a rise in haemoglobin and red blood cells.

RED CELL COUNT

Red cell count (RCC) and mean corpuscular volume (MCV) reflect the size and mean corpuscular haemoglobin (MCH) and mean corpuscular haemoglobin concentration (MCHC) reflect the haemoglobin concentration, of individual cells. These red blood cell indices are useful in the diagnosis of types of anaemia.

Anaemias are classified on the basis of cell size MCV as microcytic, normocytic, or macrocytic, and on the basis of the amount of haemoglobin MCH as hypochromic, normochromic, or hyperchromic. Microcytic/normochromic anaemia indicates erythropoietin deficiency in CKD.

WHITE BLOOD CELL COUNT AND DIFFERENTIAL

White blood cells are the cells in the body that fight against infections and allergens. There are five types of white blood cells, which can be split into two groups – granulocytes and agranulocytes. The granulocytes include neutrophils, eosinophils, and basophils and have granules in their cell cytoplasm; they also have a multi-lobed nucleus. A granulocyte white blood cells, lymphocytes, and monocytes do not have granules and have non-lobular nuclei. They are sometimes referred to as mononuclear leukocytes.

The normal range for total white blood cell count is $4\text{--}11 \times 10^9$ per litre. A low white cell count is referred to as leukopenia and a high white cell count as leukocytosis. Leukocytosis is usually due to an increase in one of

Table 2.3 Normal values – haematological tests.

Haemoglobin	Male 135–180 g per litre Female 115–165 g per litre
Haematocrit	Male 40–55% Female 35–45%
Platelets	$150\text{--}450 \times 10^9$ per litre
Leukocytes (white bloodcells)	4.5–10 g per litre

the five types of white blood cells and is given the name of the cell that shows the primary increase (i.e. neutrophilia, eosinophilia, basophilia, lymphocytosis, and monocytosis). Leukocytosis may be indicative of an infection, inflammation, or a haematologic malignancy, and leukopenia may be due to bone suppression or replacement, hypersplenism, or deficiencies of cobalamin or folate.

COAGULATION

In circulating blood, a series of factors are present that provide the means for clot formation as appropriate when damage to a vessel occurs. Prior to many kidney procedures, such as kidney biopsy, it is standard practice to ascertain that the patient has normal clotting function to avoid the risk of haemorrhage. Those with uraemia are more prone to bleeding as urea affects platelet function.

Included in this group of tests are platelets (normally, $150\text{--}450 \times 10^9$ per litre included in the full blood count [FBC]). Platelets adhere to each other and initiate the clotting cascade when damaged endothelium is encountered. Platelet deficiency (thrombocytopenia) is a common cause of prolonged bleeding.

Other coagulation studies likely to be encountered in kidney investigations include the bleeding time (normal <10 minutes); partial thromboplastin time (PTT); activated partial thromboplastin time (APTT); fibrinogen; and international normalised ratio (INR). Most methods in current use require a very precise amount of blood in coagulation tests; the blood sample should exactly reach the marked line. Blood for coagulation studies during or immediately post-haemodialysis or from heparinised lines (e.g. temporary or permanent dialysis catheters) should not be taken from a central line as the result will be inaccurate – it is recommended to use a vein instead.

FURTHER INVESTIGATIONS FOR RENAL ANAEMIA

Anaemia is a major complication of CKD and a contributory factor to cardiovascular disease in patients needing dialysis (Portolés et al. 2021). The major cause is the lack of production of the hormone erythropoietin, which is produced by the kidney. There are clinical benefits associated with correcting renal anaemia, including improved cardiac function and quality of life, and reducing the decline in kidney function in the early stages of CKD.

SYMPTOMS OF ANAEMIA

These include lethargy, dyspnoea, headache, dizziness, palpitations and pallor, and decline in exercise tolerance, sexual function, and cognitive function.

Prior to the commencement of treatment, some basic investigations must be completed in order to correct any deficiencies that may prevent an adequate response to this very expensive therapy. It is also important to exclude or treat (if possible) underlying causes such as:

- iron deficiency;
- blood loss;
- infection or inflammatory disease;
- hyperparathyroidism;
- aluminium toxicity;
- vitamin B₁₂ and folate deficiency;
- haemolysis;
- haemoglobinopathies.

OTHER ANAEMIA INVESTIGATIONS

Having ascertained that the patient has renal anaemia, the next step is to carry out certain investigations to check that there is no condition present that may prevent or reduce the effect of ESA therapy for anaemia. These tests should be repeated if diminished or non-response to ESAs occurs at a later date.

Haematinics

To maintain the haem component of the healthy red blood cell, an adequate amount of available and stored iron must be present. Several tests can be carried out to determine this very important factor – the main cause of non-response to ESAs has been found to be low available iron. Iron-deficiency anaemia is either absolute or functional.

Ferritin

The normal range in health is 30–200 µg per litre. Iron deficiency anaemia in CKD is indicated if ferritin is less than 100 µg per litre and should be reviewed if >500 µg per litre and not be allowed to exceed >800 µg per litre (Mikhail et al. 2017; NICE Guideline 2015). Ferritin is the main form of stored iron found in all tissues, but especially in the liver, spleen, and bone marrow. Ferritin found in the serum relates to the amount of stored iron but is not necessarily

an accurate assessment of available iron. Unless ferritin levels are at least $>100 \mu\text{g}$ per litre before commencing treatment with ESAs therapy, the response will be short lived. A false high level can be seen in infection and inflammatory states, indicated by an elevated CRP.

Transferrin saturation rate

Iron is transported by the specific plasma protein transferrin (or siderophilin). A useful test of available iron for red cell production is the transferrin saturation rate. Transferrin saturation indicates how much iron is circulating in the plasma relative to total iron-binding capacity. Less than 20% is indicative of iron deficiency anaemia; however, it is not a reliable test and requires sequential readings to determine an average. Ferritin and transferrin saturation rates should not be used alone to monitor iron deficiency (NICE Guideline 8, 2015).

Serum iron

Serum iron (standard reference range varies between laboratories) in those with CKD is of no great significance (except in iron overload) but is necessary for calculating transferrin saturation rate.

Red-cell folate

Folic acid is a water-soluble vitamin in the B-complex group that is absorbed from the duodenum and jejunum. Folic acid works along with vitamin B₁₂ and vitamin C to help the body digest and utilise proteins and to synthesise new proteins when they are needed. It is necessary for the production of red blood cells and for the normal DNA synthesis and affects erythrocyte precursors. Low levels can cause macrocytic anaemia. Stores of this vitamin last only a few months.

Vitamin B₁₂

Vitamin B₁₂ (normal range 140–1000 ng per litre) is a water-soluble vitamin that is part of the vitamin B complex. It is absorbed in the ileum. The uptake is dependent on the production of acid and intrinsic factor in the stomach, adequate oral intake, and production of transcobalamin (transport protein). Vitamin B₁₂, like the other B vitamins, is important for metabolism, and helps in the formation of red blood cells and in the maintenance of the central nervous system. Although the body stores can last several years without oral intake, low levels (e.g. in pernicious anaemia) can cause a macrocytic anaemia.

As folic acid and vitamin B₁₂ are water soluble, they are both lost during haemodialysis, which can lead to dialysis-induced deficiency.

OTHER HAEMOLYSIS INVESTIGATIONS

Haptoglobins

Haptoglobin is an acute-phase protein, rising in concentration during acute inflammation. Classically, a low haptoglobin concentration is indicative of intravascular haemolysis. It may also occur in extravascular haemolysis – some free haemoglobin leaks from the phagocytic cells of the spleen, chronic liver disease, metastatic malignancy, and sepsis.

Lactate dehydrogenase (LDH)

This is an enzyme that is found throughout the body in the tissues with low levels found in the circulating blood. Elevated levels occur when there is damage to the tissue as the enzyme is released from body tissue into the bloodstream. It is used to assess acute and chronic liver damage, monitor progressive diseases (e.g. liver, kidney, and malignancy) and to diagnose haemolytic anaemia.

Reticulocytes

Reticulocytes (normal range in men 0.5–1.5%, in women 0.5–2.5%) are immature red blood cells that have been newly released from the bone marrow, and can be recognised as such for about 48 hours before reaching a mature state. Patients with renal anaemia have a depressed reticulocyte count before ESA therapy and a rise should be seen when stimulation of erythrocyte production occurs as a response to ESAs. If no response occurs, further investigation should be considered. Measurement as recommended by NICE Guideline (2015) to diagnose iron deficiency and determine potential responsiveness to iron therapy is to use

- percentage of hypochromic red blood cells, %HRC $> 6\%$ – assesses how much iron is being incorporated into the red blood cell. This test can only be used if the sample can be processed within six hours.
- if this is not possible, then the use of reticulocyte Hb content CHr $< 29 \text{ pg}$ or a reticulocyte equivalent test. This test is a more sensitive test and shows the content of young reticulocytes as well, so it gives a picture of the availability in a few days.

Transferrin saturation and serum ferritin should be used if these tests are not available or the person has thalassaemia or thalassaemia trait.

URINE INVESTIGATIONS

Urinalysis plays an important part in the assessment of kidney disease. This includes visual assessment, urinary dipstick, and microscopic examination. The quantity of

Table 2.4 Normal volumes of urine.

Healthy adult	1–1.5 litres per day
Newborn baby	50–300 ml per day
Infant	350–550 ml per day
Child	500–1000 ml per day
Adolescent	700–1400 ml per day

urine passed during the day together with its specific gravity also gives an indication of kidney function. Table 2.4 lists the normal volumes of urine passed per day. Urine is composed of about 95% water and 5% solids, mainly urea and sodium chloride. It is slightly acidic (pH 6.0) and has a specific gravity of 1.010–1.030 (specific gravity of water = 1.000).

URINALYSIS

Low urinary pH can be associated with eating acidic fruits, respiratory or metabolic acidosis, high protein diet, diabetes, diarrhoea, or anorexia. High urinary pH can be associated with a low carbohydrate diet, renal calculi, respiratory or metabolic alkalosis, or UTI.

URINE APPEARANCE

Urine can vary in colour from pale straw to dark amber.

- Pale urine may be dilute due to:
 - heavy fluid intake;
 - polyuria due to kidney disease where the tubules fail to reabsorb water;
 - diabetes insipidus or diabetes mellitus.
- Dark urine may indicate:
 - concentration due to fluid depletion;
 - presence of bile.
- Haematuria can vary in appearance from ‘smoky’ to ‘tea’ to red, either bright or dark.
- Coloured urine can be caused by blackberries, beetroot in the diet and other vegetable food dyes, porphyria, and some medications. For example, orange-coloured urine is caused by rifampicin or senna.
- Frothy urine indicates heavy proteinuria or presence of glucose; however, it may occur with an old urine sample.
- Smoky urine may indicate the presence of bleeding from the kidney.

- Deposits or cloudy/turbid urine. This can occur when the urine sample is left to stand, may be crystals of phosphate, oxalate or urates, or due to pus in the presence of infection.
- Pink to black/brown (coca cola) urine may indicate the presence of myoglobin; dark brown may indicate iron supplementation, or urobilin.

DIPSTICK TESTS

Dipstick tests can be carried out in the clinic or ward situation as well as in the laboratory. Dipsticks are available that accurately show the presence of a variety of substances which may occur in the urine (for example, protein, glucose, ketones, blood, leucocytes, and nitrites) as well as giving the pH of the urine sample. The stick should be briefly dipped into a fresh sample of urine and read after 1 minute or according to the manufacturer’s instructions.

OSMOLALITY

Osmolality (normal 500–800 mOsm per kg) measurement indicates the kidney’s ability in concentration and dilution and is considered more reliable than measuring the specific gravity, and requires collection of an early-morning urine sample.

GLUCOSE

The presence of glucose may indicate diabetes mellitus, proximal tubular dysfunction, Fanconi’s syndrome, glomerulonephritis, or nephrotic syndrome.

BLOOD

The presence of blood in the urine is either microscopic – invisible – or macroscopic – visible to the naked eye. Microscopic haematuria is often an incidental finding but requires further investigation to assess for kidney disease or malignancy if > +1. Two to three positive results are indicative of persistent invisible haematuria on two or three separate occasions. Reagent strip testing is recommended and not the use of microscopy. It is also important to establish the cause is related to a urinary tract infection, and rule out other causes such as menstruation, sexual intercourse, trauma, e.g. urinary catheter, too much exercise, or an old sample (lysis of red blood cells).

PROTEIN

Although protein is a normal urinary constituent, the average daily excretion is <150 mg per day. Albumin accounts for approximately 15% of normal daily excretion,

with the other 85% made up of plasma proteins and Tamm-Horsfall protein. Proteinuria is either transient or persistent in nature.

CAUSES OF PROTEINURIA

- Glomerular (most common) includes primary and secondary glomerulonephritis (e.g. diabetes, SLE).
- Tubular includes tubulointerstitial nephritis (e.g. nephrotoxic medications such as tetracycline) and lead.
- Overflow includes multiple myeloma, myoglobinuria, haemoglobinuria.
- Secretory includes inflammatory such as UTI, urinary tract tumours.
- Transient episodes include intercurrent illness, excessive exercise, acute metabolic crisis, congestive cardiac failure.
- Orthostatic or postural hypotension.

Measurement and quantification of proteinuria is an important diagnostic tool and useful in the early detection of kidney disease. Proteinuria is an independent risk factor of CVD, death, and ESKD in the general population and in CKD patients, and there is a higher mortality rate in critically ill patients.

If proteinuria is not treated, it will lead to loss of kidney function. Protein cannot be measured on dipstick unless it is sensitive to very low levels of albumin. Nephrotic syndrome is diagnosed when proteinuria is ≥ 350 mg per day. It is important to rule out a urinary tract infection or orthostatic hypotension.

MICROALBUMINURIA

This is defined as persistent small amounts of albumin not determined by the usual dipstick test. It is used to categorise CKD (see Chapter 6).

ALBUMIN : CREATININE RATIO

The NICE Guideline (2017) recommends the use of albumin : creatinine ratio (ACR) in preference to protein : creatinine ratio (PCR) as it cannot detect low levels of albumin, i.e. <15 mg mmol⁻¹. ACR is an effective diagnostic investigation for the early detection of kidney disease and if not treated can lead to deterioration of kidney function. It is also a strong predictor of CVD and death. An ACR measures the concentration of albumin and creatinine, has a greater sensitivity in detecting low levels of proteinuria, and should always be used in diabetes (see Chapter 6 for interpretation of results).

- Normal range: ACR <3 mg per mmol.
- ACR 3–70 mg per mmol, a repeat early-morning sample should be taken.
- If ACR ≥ 70 mg per mmol, no repeat test required.

MYOGLOBIN LEVELS

Myoglobinuria may occur due to conditions such as rhabdomyolysis where there is a breakdown of muscle tissue, causing the release of myoglobin into the bloodstream. This may occur due to trauma or crush injury, seizures, or severe exercise. Myoglobin is nephrotoxic and large amounts of this protein can cause the occlusion of the renal tubules, leading to acute tubular necrosis and AKI. This can be diagnosed by a sample of urine – usually the first sample of the day.

URINE MICROSCOPY AND CULTURE

Microscopy will reveal information from the sediment found in urine – casts, crystals, blood cells, and bacteria. The site of origin of casts can often be determined, indicating the type and extent of damage to the kidney. It is normal to find red blood cells in urine at approximately <2 hpf (high power field) and these normally originate from the renal pelvis, ureter, or bladder and are uniform in shape and size. Leukocytes are also present at approximately <2 hpf, but the presence of eosinophils can be indicative of an allergic interstitial nephritis.

CASTS

Different types of casts found in the urine may indicate underlying conditions. Hyaline casts, known as Tamm-Horsfall proteins, originate from the renal tubules. They may be present due to the use of diuretics, fever, and exercise; however, they may also be present in kidney disease (for example, pyelonephritis). Granular or cellular casts may be seen in renal parenchymal disease. Red cell casts indicate bleeding and white cell casts indicate pyelonephritis or renal parenchymal disease.

If microorganisms are found to be present in the urine specimen the laboratory will provide information as to which antibiotic is most appropriate. The presence of multiple organisms may indicate contamination of the sample.

A positive microscopy sample shows at least $>10^5$ cfu per ml and organisms 1–10 hpf; below this figure is not considered significant. However, with very dilute urine, a false-negative result may occur despite infection being present.

KIDNEY FUNCTION TESTS

In CKD, a regular assessment of kidney function can be useful in monitoring the decline in kidney function and in predicting the time when KRT is likely to be needed. GFR tends to decrease in a linear fashion over time in progressive kidney disease and so, by extrapolation, predictions can be made as to when ESKD may occur (see <https://www.kidneyfailurerisk.co.uk>). Measuring GFR provides details of the filtration rate of the functioning nephrons.

Knowledge of the amount of nephron damage is useful in assisting in making the choice of suitable drug regime. When there is more than 30% of nephron loss, certain drugs should be avoided or used with caution because of the slow excretion of the drug or its metabolites. GFR often declines with age (as much as 1 ml per min each year), starting at the fourth decade.

- Increased GFR can occur with:
 - increased protein intake;
 - diurnal variation;
 - pregnancy.
- Decreased GFR can occur with:
 - exercise;
 - low-protein diet;
 - liver disease.

ESTIMATED GLOMERULAR FILTRATION RATE

The eGFR (calculated from serum creatinine results) provides the best overall assessment of the level of kidney function. However, creatinine clearance estimation (using 24-hour urine collection) can be helpful in the following situations:

- Estimation of GFR in individuals with exceptional dietary intake (vegetarian diet, creatine supplements) or decreased muscle mass (amputation, malnutrition, muscle wasting).
- Assessment of diet and nutritional status.

Kidney function in adults should be evaluated using the Chronic Kidney Disease Epidemiology Collaboration (CKD-EPI) creatinine equation, using laboratory values standardised to isotope dilution mass spectrometry (IDMS), which is validated and now the recommended eGFR formula (NICE 2014). This equation takes into account the serum creatinine concentration and the following variables:

age, gender, and race. However, caution is required in interpreting the results in those people with muscle wasting disorders and body builders, respectively, due to the problem of overestimation and underestimation (Zamon et al. 2013).

CKD-EPI EQUATION

$$141 \times \min(S_{Cr/k,1}) \propto \max(S_{Cr/k,1})^{-1.209} \\ \times 0.993^{Age} \times 1.018(\text{if female}) \times 1.159(\text{if black})$$

- k is 0.7 females and 0.9 in males.
- $\propto$ is -0.329 for females and -0.411 for males.
- min indicates the min $S_{Cr/k,1}$.
- No weight is required as normalised to 1.73m² body surface area (BSA).

eGFR CYSTATIN C

The eGFR Cystatin C diagnostic calculation was developed in 2012, and estimates GFR from serum cystatin C, age, and sex. It is less affected by age, sex, and ethnicity. NICE guidance (2014) has recommended using eGFRcystatinC at initial diagnosis to confirm or rule out CKD in people with:

- an eGFRcreatinine of 45–59 ml per min/1.73m², sustained for at least 90 days; and
- no proteinuria (ACR less than 3 mg per mmol) or other marker of kidney disease.

In AKI, the use of serum creatinine, rather than eGFR, is recommended. eGFR should not be used in those <18 and >90 years or in pregnancy (NICE 2014). Prior to measuring eGFR patients should be advised to not eat meat for 12 hours before the test and for the most accurate results, the test should be processed within 12 hours.

Procedure

A 24-hour urine collection is made that will provide the urinary creatinine content (*U*) and volume (*V*). A blood sample should be taken to indicate the plasma creatinine (*P*).

The radio-labelled substance is given by intravenous injection. The patient's weight and height must also be recorded to enable the result to be normalised for the individual patient's body surface area.

Over the four hours following the injection the usual procedure is for four blood samples to be drawn from the opposite arm to the injection of the radioisotope. This is to avoid contamination from any activity still lingering around the injection site, which will falsify the result.

KIDNEY BIOPSY

Patients who are referred to the nephrology outpatient clinic with proteinuria, haematuria, or renal impairment with no obvious cause may require a kidney biopsy in order to make a diagnosis. Whilst a kidney biopsy is a fairly safe procedure, there are risks that should be taken into consideration. Risks of kidney biopsy, which are greater in AKI, are perirenal haematoma, prolonged and severe bleeding necessitating blood transfusion, and possible need for intervention (e.g., radiological embolisation or, less commonly, surgery), and, rarely, irreparable damage to the kidney requiring a nephrectomy. Kidney biopsy is contraindicated in the following:

- small kidneys
- a single kidney
- cystic kidney or hydronephrosis
- UTI, acute pyelonephritis
- obesity
- uncontrolled hypertension
- noncompliant patient
- severe anaemia
- uncontrolled coagulopathy

Procedure

Patients will be asked to empty their bladders before the procedure. Percutaneous kidney biopsy may be performed on the ward or X-ray department, under local anaesthetic. The patient lies in a prone position, with a pillow under the upper abdomen to isolate the kidney. The kidney (usually left) is identified by real-time ultrasound (US) as to position and depth and the skin is marked where the needle should be inserted. After cleaning using a full aseptic technique, the area is infiltrated with lidocaine as a local anaesthetic, and a needle is inserted into the lumbar muscle layer until the needle (14–18G) is noted to swing with the patient's respirations. The patient should be asked to hold the breath whilst the needle is advanced 5 mm at a time, leaving the needle to swing free when the patient breathes in and out. When the needle has located the kidney, more local anaesthetic should be injected.

The needle is then withdrawn, and a small incision is made at the needle exit site. An automated biopsy gun is inserted along the same pathway, making advances as the patient holds the breath (Brachemi and Bollee 2014). When the kidney is again located, the biopsy is taken with the patient holding a breath. The biopsy gun is withdrawn and the specimen obtained is immediately placed on a slide and viewed under a dissecting microscope to ascertain that the cortex, which has been obtained is large enough (about 5 mm length) to divide into three samples. If not enough cortex has been obtained, the biopsy gun is inserted again until a suitable strip of cortex has been identified. Samples are sent to the laboratory for histology (in a 10% formalin pot), for immunofluorescence (in sterile normal saline), and electron microscopy (in specific glutaraldehyde fixative, kept cold). These samples should be delivered immediately (within minutes) to the laboratory, which must have had advance warning of the biopsy. Finally, after the biopsy gun has been withdrawn, a pressure dressing is applied, and the patient is asked to remain flat in bed.

KIDNEY BIOPSY IN THE TRANSPLANT RECIPIENT

Closed percutaneous biopsies of the transplanted kidney are undertaken to support evidence of rejection and to confirm suspicion of recurrent or primary glomerular disease (see Chapter 10). The procedure is similar to the biopsy of the native kidney but more straightforward due to the superficial position of the transplanted kidney. The patient will be placed in a supine position with a pillow beneath the transplant side. The amount of tissue required in a transplant biopsy will be less than in a native kidney biopsy as fewer tests will be performed.

RADIOGRAPHIC INVESTIGATIONS

Investigations using various radiographic methods are often employed to assist diagnosis and to assess progression of kidney disease and its attendant side effects.

PLAIN ABDOMINAL X-RAY

Plain abdominal X-rays incorporating the kidneys, ureters, and bladder (KUB) indicate the size, shape, position, and the presence or absence of one or both kidneys and may be taken before other more complicated radiological procedures in order to provide an overall background picture. Most calculi may be seen as they are usually composed of radiopaque material. KUB X-rays are usually taken from

the anterior aspect. A combination of KUB and US often forms the basic routine screening in those with kidney disease.

BONE DENSITY SCAN

Also known as dual-energy X-ray absorptiometry (DEXA) scan the bone density scan measures the mineral density of bones using a low-dose non-invasive X-ray technique. The X-ray beam has two energy peaks, one aimed at the bones and the other the tissue, then the tissue amount is subtracted, providing a bone mineral density amount which indicates the strength of the bones.

SKELETAL X-RAYS

Skeletal X-rays may be performed for patients on dialysis to detect osteodystrophy, which is associated with impaired glomerular filtration and disturbed metabolism of calcium and phosphate. Those bones most likely to show the characteristic abnormalities are the phalanges, skull, pelvis, and vertebrae. Pain and deformity will ultimately develop unless imbalances of calcium and phosphate can be corrected and inadequate metabolism of vitamin D can be halted (see Chapter 13).

INTRAVENOUS UROGRAM

Also known as the intravenous pyelogram (IVP). This examination indicates the size and position of the kidneys and the anatomy of the calyces and pelvis. The ureters are also outlined by the progression of the dye containing urine to the bladder and the subsequent use of sequential X-rays, enabling any deformities in these organs to be demonstrated. The intravenous urogram (IVU) gives little useful information in advanced CKD and consequently is not the investigation of choice if more than 50% of nephron loss is suspected. If impaired kidney function is known and an IVU is indicated, a greater dose than usual of the radiopaque contrast medium may need to be given – this in itself is nephrotoxic and may exacerbate CKD, at least temporarily.

RETROGRADE PYELOGRAM

In this examination, radiopaque dye is injected directly into the upper urinary tract via a catheter inserted through a cystoscope into the ureter. A series of X-rays are performed on one or both kidneys. This test is useful in outlining stones, calyceal defects, and masses in the ureter or renal pelvis and in defining deformities such as hydronephrosis

or hydroureter. This investigation is sometimes performed after an IVU or US has demonstrated a hydronephrosis and more clarification is needed for a diagnosis.

COMPUTED AXIAL TOMOGRAPHY OR COMPUTED TOMOGRAPHY (CAT/CT) SCAN

CT scanning is used to evaluate renal cysts and masses, to stage renal tumours, assess ureteral obstruction not detected on US, and also in the diagnosis of renal calculi disease and in the diagnosis of renal vein thrombosis. CT is an X-ray technique that uses a computer to reconstruct cross-sectional images of 1 mm slices of the organ targeted. The dose of radiation is about the same as that for an IVU.

NUCLEAR MAGNETIC RESONANCE OR MAGNETIC RESONANCE IMAGING

This form of scanning involves application of a strong external magnetic field along with a radiofrequency signal that produces a current in a receiving coil proportional to the density of protons in the body organ being scanned. This signal is processed by computer to create a tomographic slice of the organ similar to a CT scan. Magnetic resonance imaging (MRI) is used to evaluate renal masses such as renal cell carcinoma as it can differentiate between solid and cystic masses. It can also be used to diagnose renal vein thrombosis. Magnetic resonance angiography can be used to evaluate patients with possible renovascular hypertension.

ULTRASOUND

US investigations have replaced some X-ray procedures (especially the IVU) to a large degree, and because this procedure does not carry the hazards associated with radiation this method can be used in women without consideration of the possibility of pregnancy. This is a non-invasive procedure where a transducer (sonar probe) is moved in close contact with the skin over the area of investigation and it can be repeated frequently, if necessary, unlike X-ray. US is especially useful in examinations of the abdominal and pelvic organs. It is widely used to determine the size and shape of the kidney, its presence and position, and the composition of cysts or neoplasms if present, and also in the diagnosis of polycystic kidney disease.

Contrast-enhanced ultrasound (CEUS) may also be used and involves administration of intravenous contrast agents, which consist of microbubbles/nanobubbles of gas.

US IN KIDNEY TRANSPLANTATION

A common cause of early transplant dysfunction includes delayed graft function. In addition, acute rejection occurs in 10–20% of all patients. This is accompanied by inflammation, which can lead to swelling of the kidney and an increase in pressure inside the organ. US can visualise any changes to the kidney and can be undertaken daily at the bedside. However, dysfunction attributed to other causes must be excluded first before considering a biopsy to diagnose rejection. Infection may be associated with graft dysfunction, but this is readily diagnosed by symptoms, routine testing of midstream specimens of urine and blood tests to check inflammatory markers as well as blood cultures. If infections is present it would be typical to start antibiotics, reduce immunosuppression and review the US for evidence of hydronephrosis

Renal vein thrombosis is a serious complication and will cause a rapid increase in size, possibly resulting in a tear of the kidney substance. If this condition is quickly diagnosed with US, rapid surgical intervention is possible, and the graft may be rescued, or a graft nephrectomy may be performed before the graft ruptures. Renal artery thrombosis may be diagnosed ultrasonically by the observation of lack of arterial inflow. For greater accuracy, duplex scanning using a combination of imaging (ultrasound) and frequency waveform analysis (see Renal Doppler studies below) is available. A contrast CT is often performed if there is suspicion of a transplant renal artery stenosis or thrombosis on ultrasound.

Early complications following transplantation include urine leaks, usually from the site of the ureteric anastomosis. These are seen ultrasonically as a fluid collection around the graft site. Later complications are obstructive lesions (e.g., ureteric strictures), which are often insidious in onset (occurring after removal of the transplant ureteric stent) and lead to deteriorating kidney function with evidence of hydronephrosis on US.

Needle core biopsy of the transplanted kidney remains the best method of detecting rejection and determining the degree of interstitial fibrosis and acute inflammation. Using US guidance of the biopsy needle, a good core of the renal cortex may be safely obtained, carefully avoiding the structures of the renal medulla and damage to the graft. US is therefore a valuable tool in the detection and diagnosis of kidney allograft dysfunction, allowing intervention and early treatment of problems.

RENAL DOPPLER STUDIES

A non-invasive US test to assess vascular flow to the kidney, for example renal vein thrombosis, renal infarction, renal artery stenosis, and evaluate transplanted

kidneys for urine outflow obstruction (seen as hydronephrosis) and features suggestive of acute rejection. CT and MRI scans are, however, more reliable to diagnosis these conditions.

RENOGRAMS

An injection of intravenous radioisotope, which is excreted via the kidneys, and a series of X-rays are taken over a 2- to 4-hour period, which enables the assessment of kidney function and tubular secretion and can indicate the position of an obstruction – no radioisotope is seen if there is a reduction in blood supply to the kidney or in the obstructed area. This investigation can be used in place of IVU if the patient is allergic to iodine contrast medium, and it is also used in transplanted patients. In renal artery stenosis, a renogram (using either DPTA or MAG 3) may be performed and then repeated, incorporating an injection of captopril as a test dose to outline any response induced – i.e. a reduction in renal blood flow in the presence of a blockage.

RENAL SCANS

There are three types of radioisotope scans that can be performed to provide data on the function of the kidneys.

First, the isotope, ^{99m}technetium-labelled diethylene-triaminepentaacetic acid (^{99m}Tc DTPA), is rapidly excreted by the kidney and shows the blood flow through the kidneys. It identifies obstructions, for example renal artery stenosis, and provides valuable information about the function and excretion capacity of the kidney. A diuretic may also be given intravenously and the patient should be well hydrated. It is not as effective if creatinine >200 µmol per litre.

The second isotope is ^{99m}technetium-labelled dimercaptosuccinic acid (^{99m}Tc DMSA), which is retained by the cells in the proximal tubules and parenchyma and enables the identification of areas of cortical scarring, contusions, and solid lesions. This will provide quantification of relative kidney function between kidneys and within a kidney.

The third is known as MAG 3, which uses the isotope ^{99m}technetium-labelled benzoyl-captoacetyl triglycerine and is a dynamic imaging scan as the isotope is rapidly excreted by the kidney via glomerular filtration or a combination of filtration and tubular secretion. The test enables visualisation of the aorta and renal perfusion. Quantification of renal blood flow can be calculated, and it identifies the overall kidney function and presence of obstruction, thrombus, emboli, and stenosis.

RENAL ANGIOGRAM

This is performed through a catheter inserted via the femoral artery (however, the brachial artery may also be used if required) and fed to the renal artery. Radiopaque contrast dye is injected and a series of fluoroscopic X-rays performed. It identifies tumours, emboli, thrombosis,

trauma, and stenosis of vessels, and can be used for transplant donor assessment and identification of bleeding site post-kidney biopsy. Caution should be taken with patients who have some degree of renal insufficiency as the dye is nephrotoxic. The most common complication of a femoral angiogram is bruising, false aneurysm, haemorrhage, infection, reaction to the contrast agent, and haematoma.

REFERENCES

- Bennett, P.N., Brown, M.J., and Sharma, P. (2012). *Clinical Pharmacology*, 11e. Edinburgh: Churchill Livingstone Elsevier.
- Bergmann, C. (2015). ARPKD and early manifestations of ADPKD: the original polycystic kidney disease and phenocopies. *Pediatric Nephrology* 30: 15–30. <https://doi.org/10.1007/s00467-013-2706-2>.
- Bertsias, G.K., Tektonidou, M., Amoura, Z. et al. (2012). Joint European League Against Rheumatism and European Renal Association–European Dialysis and Transplant Association (EULAR/ERA-EDTA) recommendations for the management of adult and paediatric lupus nephritis. *Annals of the Rheumatic Diseases* 71 (11): 1771–1782.
- Brachemi, S. and Bollee, G. (2014). Renal biopsy practice: what is the gold standard? *World Journal of Nephrology* 3 (4): 287–294.
- Brennan, E., McEvoy, C., Sadlier, D. et al. (2013). The genetics of diabetic nephropathy. *Genes* 4: 596–619.
- Calvet, J. and Grantham, J. (2001). The genetics and physiology of polycystic kidney disease. *Seminars in Nephrology* 21 (2): 107–123.
- Cunard, R. and Kelly, C.J. (2003). Immune-mediated renal disease. *Journal of Allergy and Clinical Immunology* 111 (2): S637–S644. <https://doi.org/10.1067/mai.2003.126>.
- European Society of Cardiology (2017). ESC guidelines on the diagnosis and treatment of peripheral arterial diseases, in collaboration with the European Society for Vascular Surgery (ESVS). *European Heart Journal* 1–60.
- Forbes, J.M. and Cooper, M.E. (2013). Mechanisms of diabetic complications. *Physiological Reviews* 93: 137–188.
- Harris, P.C. and Torres, V.E. (2014). Genetic mechanisms and signaling pathways in autosomal dominant polycystic kidney disease. *The Journal of Clinical Investigation* 124 (6): 2315–2324.
- Hodson, E.M., Willis, N.S., and Craig, J.C. (2007). Corticosteroid therapy for nephrotic syndrome in children. *Cochrane Database of Systematic Reviews* (4): CD001533. <https://doi.org/10.1002/14651858.CD001533>.
- Jenkins, G.W. and Tortora, G.J. (2013). *Anatomy and Physiology from Science to Life*, 3 ed. John Wiley & Sons, Inc.
- Jenks, S., Yeoh, S.E., and Conway, B.R. (2014). Balloon angioplasty, with and without stenting, versus medical therapy for hypertensive patients with renal artery stenosis. *Cochrane Database of Systematic Reviews* 2014 (12): CD002944. <https://doi.org/10.1002/14651858.CD002944.pub2>.
- Jun, M., Lv, J., Perkovic, V., et al. (2011). Managing cardiovascular risk in people with chronic kidney disease: a review of the evidence from randomized controlled trials. *Therapeutic Advances in Chronic Disease* 2 (4): 265–278.
- KDIGO (2012). Clinical practice guideline for the evaluation and management of chronic kidney disease. *Kidney International. Supplement* 3: 1–150.
- Kidd, J. and Carl, D.E. (2016). Renal amyloidosis. *Current Problems in Cancer* 40: 209–219.
- Marshall, R.H., Schiffman, M.H., Winokur, R.S., et al. (2014). Interventional radiologic techniques for screening, diagnosis and treatment of patients with renal artery stenosis. *Current Urology Reports* 15: 414.
- McGrogan, A., Franssen, C.F., and de Vries, C.S. (2011). The incidence of primary glomerulonephritis worldwide: a systematic review of the literature. *Nephrology, Dialysis, Transplantation* 26 (2): 414–430.
- McLaughlin, K., Jardine, A.G., and Moss, J.G. (2000). ABC of arterial and venous disease. Renal artery stenosis. *British Medical Journal* 320: 1124–1127.
- Mikhail, A., Brown, C., Williams, J., et al. (2017). *The Renal Association Clinical Practice Guideline. Anaemia of Chronic Kidney Disease*. London: The Renal Association.
- Nagai, T., Yasuoka, Y., Izumi, Y. et al. (2014). Reevaluation of erythropoietin production by the nephron. *Biochemical and Biophysical Research Communications* 449 (2): 222–228.
- National Institute for Health and Care Excellence (NICE) (2014). *Chronic Kidney Disease in Adults: Assessment and Management*, Clinical Guideline, 182. London: National Institute for Health and Care Excellence.
- National Institute for Health and Care Excellence (NICE) (2015). *Chronic Kidney Disease: Managing Anaemia*. London: National Institute for Health and Care Excellence.
- National Institute of Health and Care Excellence (NICE) (2016). *Cardiovascular Disease: Risk Assessment and Reduction, Including Lipid Modification*, Clinical Guideline 181. London: National Institute of Health and Care Excellence.
- National Institute of Health and Care Excellence (NICE) (2017). *Type 2 Diabetes in Adults: Management*. London: National Institute of Health and Care Excellence.

- Nursing & Midwifery Council (NMC) (2015). *The Code. Professional Standards of practice and Behaviour for Nurses and Midwives*. London: NMC.
- Portolés, J., Martín, L., Broseta, J.J. and Cases, A. (2021). Anemia in chronic kidney disease: from pathophysiology and current treatments, to future agents. *Frontiers in Medicine* 8: 642296.
- Sasatomi, Y., Sato, H., Chiba, Y. et al. (2007). Prognostic factors for renal amyloidosis: a clinicopathological study using cluster analysis. *The Japanese Society of Internal Medicine* 46 (5): 213–219. <https://doi.org/10.2169/internalmedicine.46.1690>.
- Shitara, Y., Horie, T., and Sugiyama, Y. (2006). Transporters as a determinant of drug clearance and tissue distribution. *European Journal of Pharmaceutical Sciences* 27: 425–446.
- Steddon, S. and Sharples, E. (2015). *Chronic Kidney Disease – Mineral and Bone Disorders (CKD-MBD)*. London: Renal Association.
- Thomas, S. and Karalliedde, J. (2015). Diabetic nephropathy. *Medicine* 43 (1): 20–25.
- Tortora, G.J. and Derrickson, B.D. (2007). *Introduction to the Human Body, the Essentials of Anatomy and Physiology*, 7e. Hoboken, NJ: John Wiley & Sons, Inc.
- Tortora, G.J. and Nielsen, M.T. (2009). *Principles of Human Anatomy*, 11e. Hoboken, NJ: John Wiley & Sons, Inc.
- UK Renal Registry (2022). UK Renal Registry 24th Annual Report – data to 31/12/2020, Bristol, UK. Available from <https://ukkidney.org/audit-research/annual-report> (accessed February 2022).
- Ulinski, T. and Aoun, B. (2012). New treatment strategies in idiopathic nephrotic syndrome. *Minerva Pediatrics* 64 (2): 135–143.
- Vestra, M.D. and Fioretto, P. (2003). Diabetic nephropathy: renal structural studies in type 1 and type 2 diabetic patients. *International Congress Series* 1253: 163–169.
- Zaman, T., Filipowicz, R. and Beddhu, S. (2013). Implications and importance of skeletal muscle mass in estimating glomerular filtration rate at dialysis initiation. *Journal of Renal Nutrition* 23(3): 233–236.

RESOURCES

www.diabetes.org.uk (accessed 30 May 2024)

www.kidney.org.uk (accessed 30 May 2024)

www.patient.co.uk (accessed 30 May 2024)

www.renal.org (accessed 30 May 2024)

CHAPTER 3

Patient and Carer Involvement in Kidney Care, Education, and Research

Brian Gracey, Linda Gracey, Fiona Loud¹, and Nicola Thomas²

¹ Kidney Care UK, Alton, UK

² London South Bank University, London, UK

LEARNING OUTCOMES

- to explain what is meant by patient involvement.
- to understand the challenges faced by patients and carers during advanced kidney care, dialysis, and transplantation.
- to identify how patients and carers can be involved in kidney nursing education.
- to review the policy guidance on involving patients and carers in kidney nursing research.

INTRODUCTION

This chapter aims to provide the reader with an insight into how patients and carers can have a more participatory role, not only in the planning, delivery, and evaluation of their care but also in the teaching of nurses and involvement in research and quality improvement programmes. This chapter has been written in collaboration with people who live with kidney disease and who feel passionate about improving the nursing care that is given to everyone with the condition, whether they be contemplating dialysis options, undergoing dialysis, or receiving a kidney transplant. Parts of the chapter have been written in the first person as they are based on personal experiences, and it was felt that key messages in this chapter are more powerful if described in this way.

The chapter includes case studies and learning activities that will assist the reader to make sense of, and learn about, patient and carer partnership and involvement. The driving theme is that there should be ‘no decision about me, without me’, epitomised in the white paper *Equity and*

Excellence: Liberating the NHS (Department of Health 2010), which emphasised shared decision-making and promotion of partnership.

PATIENT INVOLVEMENT IN CARE

Patient involvement is a complex concept, and the term is sometimes used interchangeably with *partnership* and *participation*, although these similar terms are slightly different. Generally, patient involvement can be described as ‘approaches which engage individual patients in the management of their health and healthcare and in the decisions that are made in the course of it’ (National Voices 2018). The NHS Constitution states, ‘You have the right to be involved in discussions and decisions about your healthcare, and to be given information to enable you to do this’ (Department of Health and Social Care, updated 2023).

The Care Quality Commission in England published a report ‘Better Care in My Hands’, which looked at how people were being involved in their own care (CQC 2016).

The report's key conclusions were that just over half of patients definitely felt involved in decisions about their healthcare and treatment, although there has been little change in people's perceptions of how well they are involved in their health or social care over the last 5 years. A significant minority of people consistently reported only feeling involved in their care to some extent or not at all over this period. From 2020 onwards, respondents to the National UK Inpatient Survey were asked, *'To what extent did staff looking after you involve you in decisions about your care and treatment?'* In 2022, 38% said they were involved 'a great deal', 38% said they were involved 'a fair amount', but 8% said they were 'not at all' involved in decisions about their care and treatment. The proportion of respondents who claimed to be 'not very much' or 'not at all' involved increased from 18% in 2020 to 25% in 2022.

PATIENT-REPORTED EXPERIENCE MEASURES

In 2016, a pilot patient experience survey was developed by Kidney Care UK and the UK Renal Registry. The questions to be asked were devised by patients, ranging from access to the kidney team, being treated with dignity, and quality of transport; 8500 patients across 39 units responded to the paper survey. This showed a reasonably positive experience; however, transport, the environment, and sharing decisions about care showed the most variation and came out lowest.

Since then, the survey has been repeated annually and is co-designed by patients, clinicians, and researchers. As well as demographic questions that cover age, gender, ethnicity, and treatment, 38 questions cover 13 key themes that people with kidney disease say are important aspects of kidney care to them: Access to Kidney Team; Support; Communication; Patient Information; Fluid and Diet; Needling; Tests; Shared Decision Making; Privacy and Dignity; Scheduling and Planning; How The Kidney Team Treats You; Transport; The Environment.

In 2022, people reported a slight increase in their overall experience of care, with an average score of 6.25 out of 7. However, 'Sharing Decisions' was found to be one of the lowest rated themes. As in previous years, issues with communication, particularly individuals wanting better communication, featured as quite a negative aspect of care. Additionally, lack of information was an issue, particularly in relation to adequate updates about treatment, progress, and transplant prospects. More access to advice about diet, fluid intake and exercise was also requested. Full results can be found at the UK Kidney Association website (UK Kidney Association 2023).

Although most nurses, if questioned, welcome the idea of patient involvement in their care, some patients may have different experiences. The chapter includes two case studies (Case Studies 3.1–3.2) where one patient and one carer, describe care and management that did not always involve them and discuss ways in which the nursing care could have been improved.

CASE STUDY 3.1 Thoughts of a patient undergoing dialysis and a transplant

I have had kidney disease for 37 years. Having been diagnosed with renal artery stenosis in 1977, I received my first kidney transplant from my mother in 1988. That kidney settled down within 12 months and I was fortunate to spend the following 18–19 years in relatively good health, working, helping my wife bring up a young family, and travelling the world over. In 2006, my kidney began to fail, and I took early retirement from my job in June 2007. I had end-stage kidney disease in 2008 and began what turned out to be three-and-a-half years of haemodialysis. Late in August 2011, I received a call to say that there was a possibility of a kidney (transplant) for me. Twelve months after the operation, I began to lead a new life again with my wife, with the opportunity once again to travel and to do those things that I have been unable to do for so long.

I would like to share my experiences of the care I have received over the years, both of the good things, of which there have been many, but also those things that I believe could be improved.

Kidney care has different requirements from many other medical conditions, as it very often supports a situation that is chronic and therefore enables a whole life relationship to develop between the patient and the clinical team. This, to me, should be the core of kidney care. Over the years I have received excellent care, but there have been occasional lapses. It is rarely due to a lack of medical knowledge or experience; it is much more a straightforward lack of understanding of the patient's needs and concerns. Although I will largely restrict myself to my more recent experiences, it is worth recalling my shock and horror when I was told, having been an outpatient for a number of years in the mid-1980s and fully believing that I could happily continue as an outpatient, that I would have to receive dialysis or a kidney transplant relatively soon in the future. I had had no idea about this and was convinced that my life was at an end. I had two very young boys at the time, and I found it very difficult to come to terms with this news

(Continued)

CASE STUDY 3.1 (Continued)

sitting on my own facing the consultant and with no idea what to ask, what to say, and how to respond. We have come a long way since those days, but some of the lessons today are not that different.

ADVANCED KIDNEY CARE

My first kidney (transplant) began to deteriorate in late 2006 and the standard of care I received was excellent. I was then transferred to a different section of the kidney team, whose expertise was in attempting to preserve failing kidney function for as long as possible. My wife was fully involved in the discussions, and we were both kept informed of the progress, or otherwise, of the kidney. I knew long before it was required that I would need dialysis. Of the various options for dialysis, it was explained to me that haemodialysis was likely to be the only reasonable option for me and although I understood the medical mechanics of dialysis, that it purified the blood and removed excess fluid. I had no appreciation of the psychological impact of dialysis and I was given very little help in trying to understand its impact. My introduction to haemodialysis was a brief visit to an acute dialysis unit where I was shown patients attached to bleeping machines, all looking pretty poorly. The unit was full, noisy, and it appeared to me to be barely organised chaos. I was not given the opportunity to talk to any patients in a similar position to mine and I found the visit quite disturbing. I think it was predominantly for that reason that I delayed the decision to start dialysis for longer than was medically advisable.

At each of my visits to the unit in the months leading up to starting dialysis in May 2008, I was asked how I felt and I would say I was OK, but I knew in my heart of hearts that I wasn't. I was very tired all the time. I was not able to do much around the house. I slept most of the time. My feet and legs, particularly, were very swollen and I became very breathless every time I walked more than a few hundred metres, but making that final, irrevocable decision to commence dialysis was something that I wanted to put off for as long as possible. It seemed such a big and irreversible step to make. It was my wife, at one of our regular visits, when I had responded, again, to the doctor that I was OK, who said, 'No, you are not. It is time to start dialysis'. She was right but I had left it very late and I was found to be carrying in excess of 10 kg of fluid when we tried to establish my dry weight.

STARTING DIALYSIS

There is more than one means of vascular access and the options were explained to me well. In my particular set of circumstances, there was a possibility of receiving a kidney from my brother and it was therefore suggested to me that I have a permcath installed, which is a simple procedure, and

which enables the patient to begin dialysis immediately. After some discussion, I accepted this option, and the procedure took place in mid-May 2008 and I began dialysis that same day.

It was always made clear to me that I would receive a couple of sessions at the main hospital before a more permanent slot was found for me elsewhere. Within a month, I was given Tuesday, Thursday, and Saturday evening slots at a local hospital, which were convenient for me and enabled me to drive to and from the hospital. Although it would be ideal for patients to be given a choice as to which slots they might prefer, in reality that is not possible. Each of the units I attended over the years was simply too busy and, if you were to be relocated, the choice of slot was determined by what was available, not necessarily what was ideal for the patient. I did, however, request an alternative time, since I found the evening slot difficult to adjust to. I often suffered from cramp and found it difficult to sleep when I arrived home. I was eventually given morning slots on Mondays, Wednesdays, and Fridays, and that was to be my schedule until I moved to home dialysis.

My experience at the hospital was not always good. Kidney care enables a closer relationship between patient and provider to develop than is often the case with other medical disciplines. This is particularly the case with patients on dialysis, where they will see the same nurse or group of nurses, week in, week out. A good relationship between patient and nurse is, therefore, desirable and it should, self-evidently, be combined with care and compassion. None of these qualities requires intensive training; all require a particular attitude of mind and this, in my experience, was not always there. In addition, I could see how some simple changes could improve the lot of patients on the ward, but I became increasingly frustrated at my inability to get any changes introduced while I was on dialysis.

COMMUNICATION AND EMPOWERMENT

It is important for patients to feel that they are more than just an object that needs to be treated. It can help a patient gain some self-respect if he or she assists in preparing for their treatment. This might mean taking their weight, their temperature, and perhaps their blood pressure. It could also mean learning a little about lining the machine, getting your tray ready with dialyser, needles, swabs, and so forth. Although this might mean a small investment in training from the nurses in the short term, it will help them in the longer term and it will also give patients a feeling of empowerment, which is so important for long-term treatments such as dialysis. This, though, was not my experience, and it was left to patients as to whether or not they were able to assist. The view of the nurses was that they were too busy to do anything other than connect and disconnect the patients.

Because the patients are likely to see the same nurses, week in, week out, it is not only possible but also desirable to develop a good relationship between the nurse and patient. In my experience, this did not happen until I was transferred to the self-care unit prior to dialysing at home. It was often the practice of nurses, having put the patient 'on', to sit at the computer where it was clear that they were not always working! All I am suggesting is that the nurses talk to their patients and get to know them better. It will help the nurses understand the concerns of their patients better, and it will certainly help the patients feel that they 'matter' and are not simply objects to be processed.

MONITORING

Regular visits from the consultant did not take place. Those consultations that did take place invariably took place at the bedside, rather than in the more discreet confines of the consultant's room. Although I was told I had a nominated nurse, which is a sensible concept, even when she was on duty she did not look after her nominated patients. I never managed to understand what the role of my nominated nurse was. I was on the transplant list for the time I was dialysing and was told that I should have antibody checks carried out regularly. This was not done, and I found it very difficult to get these blood tests done in the satellite unit, although I was told it was important to monitor them.

INFECTION CONTROL

Insufficient care and attention were given to monitoring for infection. In my case, I developed a nasty infection around my permcath but, despite regular attention given to that area by the nurses, as they attached and detached my line to/from the machine three times a week, it was my wife who noticed the infection, as a result of which I was immediately admitted to hospital as an inpatient and was given large doses of antibiotics to stem the infection. I had the old line removed from my right jugular vein and a new one installed in my left jugular vein. How is it possible for a nurse not to notice something that he or she looks at so regularly when they should be specifically trained to be aware of the risk of such infections in a patient with a permcath?

CANNULATION

Cannulation protocols vary considerably between nurses. It was only when I started training for home dialysis that this issue was explained to me. The two main techniques are 'buttonhole' and 'rope ladder'; each has its advantages and disadvantages but none of this was explained to patients in my unit. Without careful needling, a patient can end up with very 'lumpy' access points, which may not be necessary and can be

cosmetically very disturbing. It appeared to me that the nurses would 'needle' wherever they could, rather than following one or other of the main techniques.

HOLIDAYS

Holidays are very important for dialysis patients. It is, reasonably enough, a patient's responsibility to organise whether a slot is available at a particular centre, but procedures were not in place when this initial research had been done, to set the medical requirements in place. It was often not clear which nurse was responsible for liaising on my behalf with the holiday centre and it happened more than once that my unit contacted me on the eve of a short visit away for information on exactly where I was staying, who the contacts were, and what was needed. This is very frustrating, given that trips have to be arranged at least 6 weeks in advance and dialysing away from your main base can itself be stressful.

HOME DIALYSIS

After 2 years or so of increasing frustration, I asked one of the nurses if there were any alternatives to dialysing at the hospital three times a week. One of the better-informed nurses suggested that I might enquire about dialysing at home. This seemed to me to be an excellent option and I was able to get the assistance of a nurse recently transferred from another hospital to teach me to line the dialysis machine and, much more importantly, to needle myself. It was only then that I learnt the differences between the various needling techniques, which, in my view, all kidney nurses should know about and discuss with their patients. Training was slow at the satellite unit and there were various parts of the process that I could not be taught as there was never enough time between the am/pm and pm/evening dialysis sessions for the nurses to take the time to explain to me what I needed to do.

I was, however, finally transferred to the main hospital and I became part of the local self-care unit. Dialysis patients there were able to manage their own care at a level that suited them. Some patients dialysed at the unit independently of the nurses who simply kept a watching brief over their patients, while others were at various stages of training prior to beginning dialysis at home.

Since I had already had some basic training, I quickly completed my training and, having arranged through the hospital for an appropriate machine to be installed at home and all the necessary kit to be delivered, I began dialysing at home in November 2010, and I can quite honestly say it that it changed my life. I was given excellent care from both the nursing staff and the technical support team. Each month a nurse would visit me at home and take my blood for analysis. I was also able to arrange regular visits with the consultant. More importantly, I

(Continued)

CASE STUDY 3.1 (Continued)

felt I had regained greater control over my own life, which is so important for patients with chronic conditions. I began dialysing every other day, which meant I'd be doing a Monday, Wednesday, Friday rota one week and a Sunday, Tuesday, Thursday, Saturday rota the following week. I was, therefore, dialysing one session per fortnight more than previously, which helped me to feel a little better and relax a little more with my fluid and dietary allowances. Dialysing at home also meant that I could set my own dialysis times to suit myself and my wife, rather than following a hospital routine, which enabled us to manage our lives better and helped me to 'dialyse to live', rather than 'live to dialyse'.

It was a very positive step for me to be able to dialyse at home. It is not an option for all patients, however, and it is dependent partly on the patient's willingness to take greater control over their lives, but also on their particular domestic situation.

I would recommend that the kidney nurses should be trained always to consider which of their patients might be suitable for dialysing at home and to broach the subject with suitable patients. Many patients will not want to go down this path but, with the help also of patients who are already dialysing at home, it is always worth discussing it because it is clear that the long-term outcome for home dialysis patients can be better than for those in hospital. This may require an investment in terms of time and money, but it is one that I believe will pay dividends in the medium to long term.

I found the most difficult thing to come to terms with was self-needling, but this is not always essential. In the self-care unit it was possible to do everything for yourself, except self-cannulation. At home it is possible to train your carer to undertake the cannulation if he or she is prepared to take on the responsibility.

In my case, my wife was not involved in my training until I actually came home, when she learnt from me how to line the machine, prepare the tray, and so forth. Because dialysis takes up so much of one's life together it is important, in my view, to involve one's partner in the training from the beginning. It is easier to learn with someone else and it also gives two heads the opportunity to learn what to do should something go wrong.

PATIENT CHOICE AND SHARED DECISION-MAKING

As I researched options for dialysis, it became clear that other options to dialysing three times a week in hospital did exist – home dialysis (as I have discussed above), but also nocturnal dialysis and using a portable dialysis machine, for example. In addition, there are options available for patients to improve their chances of receiving a transplant through the swap, or paired, scheme. It may be unreasonable to expect all nurses to have knowledge of all these issues but in my experience, none of the nurses knew about any of them. It was only

when I asked some specific questions that I was told about home dialysis. This information ought to be included in basic nursing kidney training, in my opinion.

BEST PRACTICE AND PEER REVIEW

As a dialysis patient I visited the units in Penzance, Truro, Jersey, Norwich, Edinburgh (the Holiday Dialysis centre), Inverness, and Elgin. All the units were different, in a number of ways, from my home base and in each case each unit could have benefitted in some way from the experiences of others. In my view, periodic meetings of senior nurses with their peers could only be beneficial and they could discuss a whole range of issues such as exercising while on dialysis, transport, the provision of food during dialysis sessions, how personal care plans are used, the role of the social worker, and whether there might be a role for a patient representative. I am sure that there are many other subjects that would be of relevance to both nurses and patients.

TRANSPLANTATION

When I finally received the call from the hospital in August 2011, it came as a complete shock. After so many years of dialysis, it was no longer at the forefront of my mind, and I was pretty much resigned to leading a life of dialysis. After a mad rush through the night, my wife and I arrived at the hospital at 7:00 in the morning and we spent a whole day undergoing a variety of tests. We were also aware that another couple had been called. Depending on the outcome of the blood tests, one of us would be offered the kidney. This was very difficult for both of us, and for some of the time both couples even shared the same waiting room. During the day we were given a little information about the donor and the family and the circumstances surrounding the donor's death. It was explained that there was a risk, albeit a very small one, that the kidney might not work and that, if it did work, it might take some time to 'wake up' – possibly 6 weeks or more. This presented my wife and me with a bit of a problem. I was pretty stable on dialysis, and we were managing our lives as well as could be expected. Our concerns were that having waited nearly 4 years for this kidney, if it did not work, this might have an impact on my antibody levels and my chances of getting another kidney in the future. These were impossible questions to answer but they had to be asked. The general view, however, from the doctors was that there was only a small risk of the kidney not working. I should go for it. Thus, when it became clear that I was to be the fortunate recipient, we did go ahead and I went up to theatre at about 21:00 that evening.

My experiences as an inpatient immediately post my transplant operation, and during the follow-up clinic appointments were generally good.

CARE AS AN INPATIENT

On the wards, the three Cs are of paramount importance: Care, Compassion, and Communication. The standard of nursing care on the wards varied considerably from shift to shift and from day to night. In general, the day staff were more proficient than the night staff. They had a better understanding of the patient's illness, were more likely to talk to their patients (although this was still uncommon in my experience), they were more attentive, responded better to patient requests, and often had a little more time to spend with their patients.

Hygiene standards on the ward were mixed. Not all nurses or doctors wore gloves when taking blood, for example. Blood pressure cuffs were never wiped before taking a patient's blood pressure. What most shocked me, however, was when breakfast was handed out, and my Weetabix was handled with bare hands.

Some nurses would offer the patient a bed bath, but most did not. Some would actively encourage the patient to move, get up from the bed, and walk around the ward, but most did not. One nurse only in my experience went to the trouble of introducing herself to me as the patient. This is such a simple issue but so important from the patient's perspective. You really want to know who is looking after you so that you can speak to the right nurse if you want some advice, help, and so forth.

OUTPATIENT CARE AND IMMUNOSUPPRESSION

As an outpatient, I was very well treated and felt in good hands most of the time. When it is time to be discharged, there are always delays, which often seem to be the responsibility of pharmacy. This, I am sure, is difficult to avoid, but I am also sure that there must be a better, more efficient way of organising a patient's departure. This is in the interests of the patients themselves but must also be in the interests of the ward in freeing up a bed promptly.

The importance of taking one's antirejection drugs is paramount. If you fail to take them, you may lose your kidney. This needs to be stressed over and over again. I am constantly amazed at the number of patients who 'forget' to take their drugs! In addition, it is always important to emphasise the side effects of the drugs. Again, in my experience, this is

done but particular attention should be given to the effect the antirejection drugs can have on one's skin and on one's susceptibility to infection.

Rejection is a constant worry. There are no guarantees with transplantation. This is another issue that needs to be highlighted. In my experience, this is done competently. My one additional comment in this area is that there is very little attention given to the psychological needs of the patient post-transplant. Initially, it is a very worrying time. You attend clinic three times a week and there can so often be setbacks, that the whole process can be a real rollercoaster. Little thought, however, is given to this area. The appointments concern themselves with the medical side of things only. I do not know whether a counsellor is even available.

As visits to the clinic become less frequent, it becomes increasingly important for a patient to be able to monitor his or her blood results. Patients are understandably concerned about their progress and, although I was told that the hospital would contact me if there were any issues, there are sometimes occasions when issues escape the attention of the experts and, in my case, my very low white cell count was not picked up sufficiently quickly and I ended up attending hospital on a Saturday morning for an emergency procedure.

In 2013, I became a member of PatientView, which was run by the Renal Registry and which allows a patient access to a range of information about his or her care. The most critical aspect to me was being able to monitor my blood results the day following my appointment. No longer am I dependent on a call from the unit. This must ease their workload as well as helping me. For anyone with computer access and a basic understanding of how systems work, I would recommend investigating the possibility of accessing the system that has replaced PatientView, which is called Patients Know Best (<https://patientsknowbest.com/renal/>). Nurses should also inform and encourage patients to sign up.

Post-transplant, my kidney function is relatively stable and I attend outpatient appointments every 3–6 months, which I am hoping is a situation that continues for as long as possible.

CASE STUDY 3.2

Thoughts of a carer

I met my husband in 1977, just 3 months after his initial diagnosis, so my experience of living with a partner who has kidney disease has been long and varied. He told me about his medical condition right at the beginning of our relationship, but I think we were both very naïve about the implications for

our future together. His condition was managed conservatively for the next 9 years. It was always there in the background but did not impact hugely on our life.

The big change came when he was told his kidney function was deteriorating and he should start on a low-protein,

(Continued)

CASE STUDY 3.2 (Continued)

low-sodium, and low-potassium diet. This was quite hard to manage whilst providing for our two young children, as we had very little advice about how to do this. Essentially just a few diet sheets and prescriptions for the relevant special foods required. These foodstuffs were mostly unpalatable and difficult to prepare. I remember crying over the first meal that I made because it looked so meagre and awful. Thankfully these (Giovanetti) diets are no longer used.

TRANSPLANTATION

Transplantation followed about 9 months later, in January 1988, when my husband's mother donated one of her kidneys. Living transplants at the time were very unusual, with only about 5% of the total being performed in this way. Two major operations within 6 weeks and various complications over the following year, resulting in a third operation, finally stabilised my husband's condition. It was a rollercoaster, never knowing what would crop up next and not quite daring to believe that eventually it would be alright.

I can remember a mother at the school gate saying that she didn't know how I could cope with all that was happening. I thought to myself that I didn't know either, but I didn't have much choice! We did have kind friends and family, but it was still a challenging time, trying to be supportive to my husband who was struggling to maintain a positive outlook, balanced with keeping life as normal as possible for our children aged 4 and 2. The culture at the time was very much 'stiff upper lip and get on with it'. In retrospect it would have been lovely to have someone to voice my concerns to, who understood the road we were travelling.

Eventually we went on to have 19 wonderful years of normal family life, the only reminder of the transplant being the various medications that my husband took daily and the hospital visits every 3 months. However, transplantation does not cure kidney disease; it only gives respite from dialysis for the lifetime of the replacement kidney.

ADVANCED KIDNEY DISEASE

By 2006, my husband's kidney function began to deteriorate and with it his overall condition. Having to take early retirement on health grounds in 2007 was a real blow to his self-esteem; he had loved his working life. Early retirement can be a difficult transition in normal circumstances but when you feel unable to enjoy the new freedom that retirement brings because you are too tired it is very frustrating. As his condition worsened, our lives became very restricted. We were unable to do much because he felt so unwell and tired all the time. Just climbing the stairs was making him breathless and he began to dread the short walk to the station to travel for his fortnightly hospital appointments.

My husband developed sleep apnoea, which meant we could not share the same bedroom. Snoring is often joked about, but sleep apnoea is not funny – it gets to the point where you spend your whole time lying there waiting for the person next to you to take their next breath. A 24-hour monitor revealed that he was suspending his breathing up to 40 times per hour. No wonder he was exhausted all the time when he could not get any proper rest. It was not until dialysis commenced that this problem began to resolve itself, as the large amount of excess fluid he carried was gradually removed.

HOSPITAL-BASED HAEMODIALYSIS

Starting dialysis is a huge step for both the patient and the carer and should not be underestimated by clinicians. Psychologically it feels like the end of normal life, no matter how limited that 'normal life' has become. The thought of being dependent on a machine for the rest of your life unless you are fortunate enough to receive a new kidney is very daunting. The information that you receive at this stage is critical to the way that you adjust to your new life and how you cope physically and emotionally. I'm sure most patients at this stage will feel depressed, quite justifiably.

Once the decision was taken to dialyse it all happened very quickly but with little preparation in terms of what we could expect. It was very bewildering and scary. I tried to be positive and encouraging because my husband was too poorly to do it for himself.

In retrospect I felt totally unprepared for it all. I knew that it was the right thing to be doing and hoped that my husband would feel better soon, but I felt totally out of my depth. A permcath line was put in and looked a mess with bleeding and bruising all around the site for almost a week. Dialysis started immediately with the first sessions being unpleasant because he suffered from bad cramps. I dreaded asking how it had gone because I knew it was probably painful. He could not tolerate having much fluid removed in one go, so it took quite a while to establish his 'dry weight'. I felt helpless and didn't know what to do or say to support him, except that it could only get better.

If we had been able to talk to a patient who was living well with dialysis at that time, it would have made all the difference – to see that one can regain control of one's life and return to a reasonable level of health.

For 2 years my husband attended the local hospital for treatment and became increasingly frustrated with the time it took and the lack of interest in him as a person. There was no attempt to get to know him or anything about his life outside. It was as if he was a body on a bed that needed to be attached and then detached from a machine at a time that suited them. This may sound very harsh, but I can't understand why you

would choose to be a dialysis nurse if you have no interest in your patients as people when by the nature of the job you are spending long periods of time with those people every week!

In stark contrast, we have met some wonderful dialysis nurses throughout various parts of the country as my husband received treatment on holiday. Without exception, they were kind, caring, proficient, and, crucially, interested in him as an individual. Those nurses learnt more about him in a week as a holiday dialysis patient than most of those at the home unit learnt in the whole time he was there.

HOME HAEMODIALYSIS

We were eventually made aware that home dialysis might be an option and this was a real turning point. From a slow start, we eventually reached the stage where my husband could start dialysis at home. A spare room in the house was adapted and the relevant equipment was installed by the hospital. We had wonderful support from the home dialysis team but it was still quite nerve wracking when we dialysed for the first time on our own. I would say that it took about three months for us to gain confidence.

It was a big change for me as my life became much more restricted. Before, my husband would leave for the hospital at 07:00 and return at about 13:00, which did not affect me at all. I would either be at work or doing my own thing. Once the home dialysis began, I had to be at home and available the whole time that my husband was attached to the machine. I had not fully considered the implications of this and it was quite hard to adjust. He was advised that increasing the amount of dialysis he performed would improve his overall condition, which made sense, so he decided to dialyse every other day. This meant that we were on a two-week rotation, which was fine, but it also meant that I could not have the freedom to attend a regular evening class or meeting because I would not be free on the same evening every week. As I was working part time we had to dialyse in the evening when I got home. This also meant that I spent every other evening by myself as my husband preferred to be on his own during his sessions. I would be downstairs with a two-way radio so that he could call me if he needed anything. He was always hungry whilst dialysing and I would provide sandwiches, toast, and biscuits as required!

Having said all of that, home dialysis brought huge benefits, and we were so pleased to be able to take advantage of the opportunity offered. The freedom to dialyse to suit our life gave us the ability to travel and visit friends and family more easily. Taking control of the treatment rather than being dependent on the hospital was very liberating. We were free of the risk of hospital-acquired infections and, apart from the occasional visit from the home dialysis sister to take blood samples and follow-up hospital checks, we were living our own lives again. Life was at home rather than the hospital.

My husband had been on the transplant list for over 4 years and, having exhausted all other potential options, we began to accept that dialysis might have to be a permanent part of our lives. We decided to try and do as much as we possibly could within its constraints, including travelling to America to visit family. We continued to travel within the UK receiving hospital dialysis in the local units. We found an equilibrium that gave us a good quality of life.

TRANSPLANTATION

When a call finally came, I felt totally unprepared. My husband had gone away on a walking trip for a couple of nights, and I took the call in the early hours of the morning. My first reaction was that one of our elderly relatives must have been taken ill. As soon as the caller said that she was a doctor from the hospital and asked for my husband, I realised what this might mean. The range of emotions that I experienced at that moment included shock, excitement, fear, disbelief, anxiety, and, most strongly of all, sadness for the donor's family.

My husband has already described the hours that we waited to find out if the kidney would be suitable. We decided not to tell any friends or family what was happening, not wanting to raise anyone's expectations, let alone our own, just in case it did not go ahead. Then the huge sense of relief and the ensuing anxiety when we were told it was a suitable match, with the excitement of contacting everyone. Thank goodness for text messaging and email! The operation went ahead that night and I remember saying goodbye to my husband in the anaesthetic room, thinking, 'Please God let it all go smoothly'. To my amazement I received a call at about 1:00 from my husband saying that it was all done and he was back in the ward. When I visited him the next morning, he had no recollection of making the call!

From then on, I spent every day driving to and from the hospital, spending as much time with my husband as was allowed. At home I was receiving all the wonderful calls with enquiries and good wishes, but it was very tiring. Unfortunately, both of my sons and most of our good friends that I might have called on were away at the time, so it was a great relief when they all began to return and I didn't feel so alone.

My husband recovered well and focussed on getting mobilised as quickly as possible, but every day we were hoping for that precious moment when he needed to pee! It finally came on day six after the operation. I was at home and received a text from my husband as he was too emotional to speak. It is difficult to explain the relief that I felt at that moment, but it was as though a huge burden was being lifted from my shoulders. I sent out a mass text message around the world to friends and family. My son's girlfriend was on holiday with her family and burst into tears when she read it, as did her mother and sister! Never were a few millilitres of urine so welcomed! My husband

(Continued)

CASE STUDY 3.2 (Continued)

continued to make a good recovery and was discharged home 9 days after the operation. It was so good to have him at home and be able to care for him myself.

POST-TRANSPLANT FOLLOW-UP

Follow-up for patients after transplantation is very intense, requiring hospital visits three times per week for blood tests, weight, and blood pressure measurement. This was tiring for my husband, and he was anxious about travelling by train and being exposed to all the coughs and colds of other passengers with his immune system suppressed.

Over the following weeks and months there were various setbacks, mainly related to getting his immunosuppression drugs properly balanced, but eventually my husband's condition stabilised and we began to enjoy the newfound freedom that the transplant gave us. To be able to enjoy the simple things, like going out for a lovely cup of coffee and a cake! The fluid restriction and low-potassium diet had meant this was impossible before. We were able to visit friends and family when we liked for as long as we liked, and it was, and still is, wonderful.

MY THOUGHTS TO YOU AS NURSES

Kidney disease is with the patient and their families for the rest of their lives, and each one has their own individual circumstances. Learn as much as you can about them as individuals and their particular condition and you will help transform how they cope with their disease.

As a patient on hospital-based dialysis, it is very difficult to comment if things are not right, as you feel very vulnerable. Criticism, however constructive, is not always well received and therefore things that could be improved go unchanged because of lack of trust.

Being confident that those who care for you really know you will develop a sense of trust that will enable concerns to be raised and addressed. The following can improve your patient's well-being:

- In the early days of diagnosis and dialysis, patients may feel very unwell, frightened, depressed, that their life is over. There may be anxieties about their employment, finances, housing, family, and so on, which may affect their overall health.

- Spend time to get to know your patients as well as possible, understanding their home and family circumstances, their fears and concerns. Understand what they enjoy and what they can do, and focus on these things and not on the negative
- Use language that can be easily understood.
- Become their advocate.
- Encourage independence, teaching them all the things they can do to help themselves. Many patients could manage some or even most of their dialysis given the right encouragement. Some could have dialysis at home with the right support.
- Recognise that kidney disease, and dialysis in particular, has a huge impact on the patient's partner and immediate family.
- Encourage and enable the patients to take holidays by facilitating dialysis at other centres.
- Be knowledgeable about what is available. If the patient is on the transplant register, make sure the patient is aware of the various options available through living transplantation. Encourage discussion with friends and family.
- Emphasise that you 'dialyse to live, not live to dialyse'. There is still so much that they can do.

Being the partner/carer for someone with kidney disease can be very challenging and lonely at times, as it can be hard for friends and family to understand the complexities of the disease and all the challenges that it brings. My plea would be to ensure that the carers are looked after too. Small acts of kindness and comforting words will go a long way. Information about the local KPA, support groups, and online forums can provide a lifeline.

We are now many years on from the transplant, and our life is very busy and wonderful. One of our sons has married and we now have a gorgeous grandson that we are both able to enjoy to the full. We are so grateful to the family who had the courage to donate the organs of their loved one. I do hope that knowing other lives can continue restored to good health will be of some comfort to them.

REFLECTIONS ON THE CASE STUDIES

After reading the case studies above, think about similar situations when you might have been the provider of the care to these patients. Reflect carefully and consider the following points:

- What skills do you have (or what do you need to acquire) to enable a true partnership with patients?
- How far do you actively include patients and family members in decisions about their care?

- How could you make the best use of quiet times during a dialysis shift (such as assessment, supporting self-management, education, decision-making with patients)?
- In what ways could you engage with patients and their families to measure the level of patient involvement in your unit?
- How far does your unit give a true choice to patients when they are contemplating long-term kidney replacement therapy?

PATIENT AND CARER INVOLVEMENT IN KIDNEY NURSING EDUCATION

Patients are increasingly being involved in the education of healthcare professionals (HCPs) and students. Involvement has clear benefits: It helps learners develop new knowledge, skills, and attitudes contributing to person-centeredness, and it makes education more engaging, significant, and transformative (Eijkelboom et al. 2023). Early research on the involvement of users in education has demonstrated that it can challenge entrenched perceptions and attitudes of health professionals and help break down barriers of hierarchical and paternalistic services, and can produce practitioners capable of delivering improved and more relevant outcomes for users and their carers (Tew et al.

2004). For example, service user involvement in curricula development was analysed in a review (Morgan and Jones 2009), and it was found that, despite a limited and weak traditional evidence base on impact on students' knowledge and practice, both students and service users identify benefits from engagement. Another paper (Gutteridge and Dobbins 2010), which was part of a larger evaluation study, described how members of staff in a faculty of health were interviewed about the impact of service user and carer involvement on learning and teaching. Semi-structured interviews were used to explore current levels of involvement, barriers, and solutions, and findings suggested that staff recognised the need to involve service users and carers in their learning activities but a number of barriers were found.

More recently, a scoping review of 28 studies (Stretton et al. 2023) explored whether utilising patients as teachers, with autonomy over taught content, may better prepare students to deliver patient-centred care. Patient teacher programmes ranged from single, short 1- to 2-hour tutorials to longitudinal community-based programmes. The review found that these programmes are mutually beneficial for students, improving awareness of all patient-centred domains, and patients feel empowered by their roles in education.

If you are working in a clinical or academic setting, then consider how best to involve people who live with kidney disease in education of nurses. See Case Study 3.3.

CASE STUDY 3.3

Undergraduate teaching

An interesting teaching session had taken place which was designed for year 2 student nurses and taught by a kidney nursing lecturer. Patients and carers from an advisory group were invited to review what was taught and how the lecture was conducted. Patient and carer participation was encouraged at this session as it was felt that the student nurses required examples of first-hand experiences from people living with kidney disease and carers in order to supplement and enhance their learning. An evaluation was carried out following the session where the patients and carers were able to provide feedback with regards to the format/structure of the modules based on kidney care. Such evaluations provided positive changes to the kidney care modules and encouraged motivation and interest in kidney care from student nurses.

After further discussions, the academic staff decided to involve patients in all future teaching sessions. The first teaching session that involved patients and carers followed

a few months later. The views on all sides of patient, carer, and students were very positive. All enjoyed the session, and the evaluation from students felt it was very useful since it gave them a strong insight into what it is like to have kidney disease.

Of the 48 students attending the lecture, 46 gave feedback, and 100% of the feedback was positive. Examples of the comments made include:

- 'I felt like I was present in the treatment and now know how it feels to be a kidney patient'.
- 'It was interesting, concrete. It should be done as much as possible to give a human face to conditions'.
- 'It brings the subject to life. It teaches me more than what the lecturer teaches'. 'It was really helpful to have an insight into the patient's experience'.

(Continued)

CASE STUDY 3.3 (Continued)

- ‘If we are to become good nurses we need to listen to our patients. This should start now as we train’.

The response to the involvement of patient and carer in all the lectures was overwhelmingly positive. The nurses were able to obtain a first-hand view of the experiences of an individual with kidney disease together with a carer, enabling them not only to learn about kidney disease from an academic perspective but also to learn the impact this has on patients from a personal level. Many students commented on the greater impact of a session where they could understand the patient’s journey and the involvement, and importance, of a carer in their life. It was also felt that the practice of involving

a patient at such sessions should be extended to other medical disciplines. Felton et al. (2018) has supported this view by finding that the involvement of service users and carers in classroom learning is meaningful and relevant to nursing students’ education. One benefit was that the co-facilitation approach enabled students to understand the person, rather than the ‘patient’.

Overall, the sessions were enjoyable for the students and they appreciated patients and carers coming to their session and showed gratitude. For the patients and carers it was very positive to know that to the best of their ability, they helped give an informative outlook on what it is like to have kidney disease.

SUMMARY OF CASE STUDY 3.3

If setting up a similar project in your hospital or university, then it is important to consider the following:

- All lecturers/practitioners must be committed to the meaningful involvement of patients in teaching and learning.
- Patients and carers need to be reimbursed for their time and expenses (see guidelines on this in the following section).
- A formal advisory group needs to be set up with written ‘terms of reference’.
- Patients and carers may need support and/or training in teaching skills and techniques.

McKeown et al. (2010) have written a comprehensive guide to service user and carer involvement in education for health and social care if further information is required.

PATIENT AND CARER INVOLVEMENT IN KIDNEY RESEARCH

One of the first reviews to provide evidence of a range of benefits to researchers and participants of public and patient involvement and engagement (PPI/E) in health research was Staley (2009), although the importance of this approach to the NHS had long been recognised (Boote et al. 2002). There is a long history of PPI in particular fields, such as in mental health (Mental Health Research Network; Mental Health Foundation, SURE) and Cancer

(National Cancer Research Network; Macmillan Cancer Support). However, user and carer research collaboration between members of the public, researchers, and clinicians in the field of kidney care is still developing.

Barber et al. (2011) investigated the process and progress of service user involvement in research and also identified perceived benefits to research, researchers, and service user researchers that endorsed previous findings. However, this study also demonstrated the benefits of allowing time for patients’ structured reflection on their involvement, and this is an important message for those working in kidney care. A systematic review (Tong et al. 2015) of 16 studies found that the processes for identifying research priorities are broad ranging, but patient involvement is uncommon, and the processes are often not described well. Establishing research priorities, using a prespecified and transparent process that engages patients, is needed to ensure that resources are invested to answer questions that address the shared priorities in kidney disease. Since 2015, the Standardised Outcomes in Nephrology (SONG) initiative aims to establish a set of core outcomes and outcome measures across the spectrum of kidney disease for trials and other forms of research. The outcomes will be developed based on the shared priorities of patients, caregivers, clinicians, researchers, policy makers, and relevant stakeholders. This will help to ensure that research is reporting outcomes that are meaningful and relevant to patients with kidney disease, their family, and their clinicians; to support decisions about treatment. One important set of outcomes that have been developed is fatigue in haemodialysis (Ju et al. 2020).

CASE STUDY 3.4**Patient and carer involvement in quality improvement**

In 2010, Kidney Research UK, with a grant from the Health Foundation, led a project (named ENABLE-CKD) to improve the variability in managing early CKD by using a quality improvement intervention called a *care bundle* (a set of evidence-based activities grouped together and carried out at the same time) (Thomas and Loud 2012). The care bundle comprised three clinical interventions, plus one self-management intervention developed and delivered by a patient advisory group. See Case Study 3.4.

A patient advisory group was set up and comprised six people with various long-term conditions (kidney, diabetes,

heart disease). The group was led by an expert patient, previously known to the kidney community and with a background in management. The members of the patient advisory group had some common characteristics, including a shared goal of wanting to help others. The chair of the patient group created role descriptions in conjunction with team members (see Box 3.1), setting expectations in both the project and patient team that all were to be treated as equals and professionals in the project. Honoraria were paid at the same rate as professionals on the team, further demonstrating the value of working together in this way (Loud et al. 2013).

BOX 3.1**ROLE DESCRIPTION FOR PATIENT ADVISORY GROUP MEMBERS****Duration**

The term of office is the duration of the project.

Background

This group consists of people who support the aims of the project and who:

- have experience of kidney disease as service users or carers;
- represent kidney organisations;
- represent nonkidney organisations from related medical disciplines such as vascular care and diabetes care.

Role

- Guide and influence the effectiveness of delivery and propagation of educational tools for patients to improve patient care.
- Assist with measurement methods of the quality and effectiveness of tools (with reference to the expected benefits).
- Monitor and review output as tools are applied.
- Alert core team to potential risks.
- Contribute to possible practice training.
- Use work from other disease areas.
- Consider all work with reference to propagation in other disease areas.
- Use personal networks to spread awareness of the programme. The group will meet two or three times each year.

Principal responsibilities

1. Attend patient group meetings.
2. Contribute during patient group meetings.
3. Take part in group communications.
4. Deal with the associated paperwork related to the project.
5. Support others in the group.
6. Respect confidentiality.

Benefits to group members

- *Personal development:* Through involvement in the full range of patient group activities, members will be offered opportunities to develop knowledge and skills in areas related to the project.
- *Personal satisfaction:* Many members are gratified that they are making a much-valued contribution to a project of potential benefit to kidney patients in the United Kingdom and beyond.
- *Payment:* Members can claim reimbursement of travel expenses and a daily fee in accordance with National Institute for Health Research (NIHR) recommendations for attendance at project meetings (NIHR 2023).

Many organisations have since involved patients and the public in improving their services. The Kidney Quality Improvement Network (KQuIP) showcases a range of examples (NIHR n.d.).

(Continued)

CASE STUDY 3.4 (Continued)

The members of the patient advisory group themselves benefited from their participation in the ENABLE-CKD project, gaining skills in training of professionals, confidence in their own condition, and satisfaction from helping others. Regular communication between advisory group members was important to project success, as was understanding and support from each other when advisory group members had their own health challenges.

Over two years the team worked alongside the clinical team and the GP practices using a quality improvement approach: Plan, Do, Study, Act (Institute for Health Improvement 2012).

TRAINING HEALTHCARE PROFESSIONALS

The team co-developed and delivered training to 29 GP practices in how to help people to self-care. Healthcare professionals appreciated the training and materials, as they were developed by people of long-term conditions it added a level of experience to the project. They valued learning how to explain kidney disease and how to support their patients to self-care.

INFORMATION BOOKLET FOR PATIENTS

The team co-developed a patient information pack, which the trained doctors and nurses would give to people with CKD who said they wanted the self-management information. A diet sheet was later added to the pack, on request from both

patients and professionals. The pack included information about CKD and where to find further information as well as a DVD called 'Living with CKD'. At the end of the project, all these materials were amended following patient evaluation.

EDUCATION FOR PEOPLE WITH CKD

The patient team co-developed and delivered patient education sessions (for people with stage 3 CKD) at selected GP practices, focusing on how people could help themselves. They explained what self-care is and what an individual can do to help themselves. The education session comprised:

- description of self-care and exploration of benefits;
- areas on which to focus for self-care;
 - blood pressure;
 - blood sugar;
 - smoking;
 - diet;
 - exercise;
 - taking medication and why it is important;
- limited consultation time with doctors/nurses – making the best use of it.

KIDNEY PATIENT INVOLVEMENT NETWORK (KPIN)

Clinicians and researchers should always seek patient involvement and participation at the outset of their project. However their involvement does not always have impactful outcomes, especially if patients feel included only as a token and are not given requisite support and training in that role. In recognition of the need to build a stronger partnership between patients and professionals, KPIN (started in 2018) has been developed by patients and professionals together. It represents many different interests, from kidney research to redesigning services that influence and improve the quality of patient care. It aims to help the patient and carer voice to be stronger and provide adequate training to increase the number of patient/public leaders. KPIN was included as a testbed for UK standards for public involvement (NIHR 2019).

Since 2018, KPIN has further developed its objectives, which now include:

- Embedding the patient and carer's voices and experiences into the planning, delivery, and evaluation of health and care services, research, and quality improvement initiatives, including service commissioning and health policy.
- Creating a network that shares good practice and resources, strengthening existing networks, and building an infrastructure that connects and coordinates patient involvement, promoting user and carer interests.

One very important aspect of their work is enabling clinicians and researchers to advertise opportunities for patients and their families to be involved in research, as members of advisory or patient groups that shape or inform research methods.

Kidney nurses who are developing a patient/advisory group as part of their quality improvement or research project, can also contact their local Kidney Patient Association (KPA) for possible members. Kidney charities also have groups of people who live with kidney disease who have expertise in involvement activities and/or

research skills. For example, Kidney Care UK has a patient advisory group and Kidney Research UK has a group called Kidney Voices for Research. Other associated charities, such as Diabetes UK and the British Heart Foundation, also have groups of people they can ask to be involved in local projects.

MEASURING THE IMPACT OF PATIENT AND PUBLIC INVOLVEMENT

Brett et al. (2014) published an early review that included 66 studies that reported the impact of PPI on health and social care research. The positive impacts identified enhanced the quality and appropriateness of research at all stages of the research process. These included development of research questions that mattered to patients, development of user-friendly information, questionnaires, and interview schedules, more appropriate recruitment strategies for studies, and enhanced implementation and dissemination of study results. There is no doubt that PPI enhances any quality improvement or research project, but healthcare professionals must take care to evaluate the impact in order for PPI to become part of everyday practice. A study (Thomas et al. 2016) designed to understand the experiences of older people (>70 years) when making a decision about kidney replacement therapy, was also a co-produced study, whereby patients and carers were involved

in all aspects of the research process. This study also explored the impact of involving people with kidney disease on the research process and the individuals who were involved. One interviewee (who had kidney disease) said, 'It helped because they (the participants) felt that you understood what they were telling you, there's almost that immediate bond' (p. 6).

PPI is now well embedded in research activities, and an explanation of how PPI will inform the research methods is a funding requirement by the NIHR, many other funders and also ethics committees. It is important to consider at what level the involvement will be (i.e. consultation, collaboration, or user-led) and when it will be (at which stages of the research process). There are numerous examples of the impact of PPI, such as securing funding, designing study protocols, choosing relevant outcomes, and achieving recruitment targets of participants (Brett et al. 2020).

CONCLUSION

This chapter has highlighted the critical importance of involving patients and carers in kidney practice, education, and research/quality improvement programmes. It is hoped that nurses reading this chapter will reflect very carefully on what has been written and evaluate how far they facilitate a true partnership with patients and their families on a day-to-day basis.

REFERENCES

- Barber, R., Beresford, P., Boote, J. et al. (2011). Evaluating the impact of service user involvement on research: a prospective case study. *International Journal of Consumer Studies* 35 (6): 609–615.
- Boote, J., Telford, R., and Cooper, C. (2002). Consumer involvement in health research: a review and research agenda. *Health Policy* 61 (2): 213–236.
- Brett, J., Staniszewska, S., Mockford, C. et al. (2014). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expectations* 17 (5): 637–650.
- Brett, J. O., Staniszewska, S., Mockford, C., Seers, K., Herron-Marx, S., & Bayliss, H. (2010). The PIRICOM Study: A systematic review of the conceptualisation, measurement, impact and outcomes of patients and public involvement in health and social care research. London: United Kingdom Clinical Research Council
- Care Quality Commission (2016). *Better Care in My Hands* <https://www.cqc.org.uk/publications/themed-work/better-care-my-hands-review-how-people-are-involved-their-care> (accessed 30 January 2024).
- Department of Health (2010). *Equity and Excellence: Liberating the NHS*. London: The Stationery Office.
- Eijkelboom, C., Brouwers, M., Frenkel, J., et al. (2023). Twelve tips for patient involvement in health professions education. *Patient Educ Couns.* 106: 92–97.
- Felton, A., Cook, J., and Anthony, R. (2018). Evaluating a co-facilitation approach to service user and carer involvement in undergraduate nurse education. *Nursing Standard* 32 (20): 47–54.
- Gutteridge, R. and Dobbins, K. (2010). Service user and carer involvement in learning and teaching: a faculty of health staff perspective. *Nurse Education Today* 30 (6): 509–514.
- Unruh, M., Davison, S., Daputo, J., et al. (2020). Identifying dimensions of fatigue in hemodialysis important to patients, caregivers, and health professionals: an international survey. *Nephrology* 25 (3): 239–247.
- Loud, F., Jain, N., and Thomas, N. (2013). How to develop a patient and carer advisory group in a quality improvement study. *Journal of Renal Care* 39 (suppl. 2): 2–9.

- McKeown, M., Malihi-Shoja, L., and Downe, S. (2010). *Service User and Carer Involvement in Education for Health and Social Care*. Oxford: Wiley-Blackwell.
- Morgan, A. and Jones, D. (2009). Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: a literature review. *Medical Teacher* 31 (2): 82–95.
- National Institute for Health and Care Research (NIHR) (2023). Payment guidance for researchers and professionals. <https://www.nihr.ac.uk/documents/payment-guidance-for-researchers-and-professionals/27392> (accessed 29 January 2024).
- National Institute for Health and Care Research (NIHR) (2019). NIHR announces new standards for public involvement in research. <https://www.nihr.ac.uk/news/nihr-announces-new-standards-for-public-involvement-in-research/23830>. (accessed 11 February 2024).
- National Institute for Health and Care Research (NIHR) (n.d.) KQuIP. <https://sites.google.com/nihr.ac.uk/pi-standards/standards> (accessed 29 January 2024).
- National Voices (2023). Making what matters to people matter in health and care. <https://www.nationalvoices.org.uk/> (accessed 29 January 2023).
- NHS England (2023). Resources for successful patient and public participation <https://www.england.nhs.uk/get-involved/involvementguidance/> (accessed 29 January 2023).
- Staley, K. (2009). *Exploring Impact: Public Involvement in NHS, Public Health and Social Care Research*. Eastleigh: National Institute for Health Research.
- Stretton B, Bacchi S, Thomas J. (2023). A scoping review of patient-led teaching of health professions students. *Intern Med J*. 53 (4): 629–634.
- Thomas, N., Jenkins, K., McManus, B. et al. (2016). The experience of older people in the shared decision-making process in advanced kidney care. *BioMed Research International* 1–8.
- Thomas, N. and Loud, F. (2012). Managing chronic kidney disease in primary care: a quality improvement study. *Renal Society of Australasia Journal* 8 (3): 152–157.
- Tong, A., Chando, S., Crowe, S. et al. (2015). Research priority setting in kidney disease: a systematic review. *American Journal of Kidney Diseases* 65 (5): 674–683.
- UK Kidney Association (2023). Kidney patient reported experience measure. <https://ukkidney.org/kidney-patient-reported-experience-measure> (accessed 13 January 2024).

RESOURCES

- Health Foundation News, blogs, events, groups and members related to Patient and Public involvement. <https://q.health.org.uk/area-of-interest/patient-and-public-involvement/> (accessed 30 January 2024)
- Health Foundation Peer Support. <https://q.health.org.uk/q-improvement-lab/lab-1-peer-support-available/> (accessed 30 January 2024)
- HealthTalk Offering patient information, patient stories and patient blogs. <https://healthtalk.org/> (accessed 30 January 2024).
- Kidney Patient Involvement Network Resources. <https://kpin.org.uk/resources/> (accessed 30 January 2024).
- NIHR Briefing notes for researchers - public involvement in NHS, health and social care research. <https://www.nihr.ac.uk/documents/briefing-notes-for-researchers-public-involvement-in-nhs-health-and-social-care-research/27371> (accessed 30 January 2024).
- Research Design Service PPI/E resources. <https://www.rds-se.nihr.ac.uk/public-involvement/patient-and-public-involvement-resources/> (accessed 30 January 2024).

LEARNING OUTCOMES

- to outline the emotional challenges individuals may present with whilst living with chronic kidney disease and kidney replacement therapy.
- to explore the importance of emotional well-being for individuals living with chronic kidney disease and kidney replacement therapy.
- to identify means of support for individuals and their partners, families, and caregivers.
- to understand the management strategies that may assist individuals and their partners, families, and caregivers to cope and adapt to this long-term condition.

INTRODUCTION

Chronic kidney disease (CKD) impacts substantially on morbidity and mortality with an international incidence of 9.1%. It is the 12th leading cause of death globally (Bikbov et al. 2020) and is anticipated to be the 5th leading cause of premature death by 2040 (Foreman et al. 2018). The incidence of CKD and kidney replacement therapy (KRT) continues to grow. CKD-associated mortality has not observed sustained progress that other long-term conditions have including cardiovascular or respiratory diseases (Bikbov et al. 2020). Persons living with a long-term illness are more than just their disease with emotional concerns just as relevant as physical. It is well documented that there are a variety of emotional challenges faced by individuals when living with CKD and whilst preparing for and undertaking KRT. This chapter aims to address the importance of emotional well-being for individuals and their partners, families, and caregivers when living with this long-term condition. It will also address how well individuals manage these emotional challenges through these life changing events of CKD and KRT. The role of the multidisciplinary team will be highlighted together with management strategies which may assist individuals and their partners, families, and caregivers to cope and adapt with the various facets of treatment modalities for kidney disease (KD).

Persons living with KD experience not just physical but emotional challenges regardless of whether they are

receiving dialysis, are transplanted, or not yet requiring KRT. They can struggle with uncertainty about their future and can experience fatigue, emotional stress, mental health concerns, sexual difficulties, fluid, and dietary restrictions, discomfort, and pain, along with a high medication burden. Furthermore, there are serious effects on quality of life (QoL), day-to-day activities, work, and participation in the social life of their partners, families, and caregivers (Vanholder et al. 2021, 2022).

Living with KD is life changing. There is no cure and treatments can be extremely burdensome; for example, attending multiple hospital appointments. Dialysis treatment is often arduous and typically necessitates that individuals spend 4 hours plus in hospital three times weekly, thereby reducing their capabilities to work and socialise (Kidney Research UK 2022). Psychological distress such as depression, anxiety, and stress are experienced by individuals receiving dialysis (Maharjan 2022). Those individuals requiring a kidney transplant (KT) can wait an extensive time frame (on average 2–3 years) before receiving a donor kidney with no assurances. They can have successful surgery; however, they live with the understanding that on average their transplant from a deceased donor lasts 15–20 years and a transplant from a living donor about 20–25 years. The longevity of these transplants is impacted by several factors such as age, health, and additional multimorbid risk factors such as diabetes and cardiovascular

complications (Kidney Research UK 2019; Kidney Care UK and the National Psychosocial Working Group 2022). These uncertainties can take a toll on the mental health of persons living with KD (Kidney Research UK 2022) and can have a substantial influence in the longer term on kidney outcomes. Therefore, both psychological and psychiatric care are essential throughout the patient's journey (Kidney Care UK and the National Psychosocial Working Group 2022).

Banks et al. (2020) on behalf of the Centre for Mental Health and Kidney Research UK (2020) issued a statement of intent concerning the importance of mental health with KD, which was endorsed by both the UK Kidney Association (UKKA) and the British Renal Society (BRS). They identified the need to collaborate to better comprehend the association between mental health and KD and to produce evidence of how treatment can be improved for those in need, as well as promoting this evidence to ensure the mental health needs of individuals with KD are also addressed by others key stakeholders within the kidney community and beyond.

Sarah Green, a patient advisor and one of the authors of this report, outlined in her own words what it is like to live with KD:

Once you're a kidney patient, you are a kidney patient for life ... Every time you are admitted or have a procedure you go into that carrying all the trauma from previous procedures. Trauma that has had time to grow and solidify in your head. Then you are made to feel like you are overreacting. This often leads to you feeling even worse. Shame, self-doubt, and criticism all mix in with the trauma and make de-escalating your reaction harder and harder. Is it any wonder those with long term health conditions are more likely to have a mental illness? I think all too often the medical professionals hugely underestimate the burden that we carry and minimise the psychological effects of this burden

(Banks et al. 2020: 1).

Kidney Research UK (2022) is continually campaigning for improved access to specialist mental health support as part of routine kidney care. They conducted a survey of 1000 adults living with all stages of KD: 68% identified that they had not been offered any mental health support; 67% acknowledged since kidney diagnosis they had endured symptoms of depression; whilst 27% disclosed that they had contemplated self-harm or suicide. This survey highlighted additional critical significances, with 36% identifying their poor mental health indicated they were not able to completely look after their physical health. It is therefore not surprising that 53% of adults surveyed acknowledged finding it difficult

to speak out about their mental health. A subsequent series of kidney conversations with individuals emphasised the struggles that they often endure with their mental health because of their kidney condition (Kidney Research UK, 2022).

Cogley et al. (2023a) established that the levels of psychological distress, mental health diagnoses, and suicide attempts was high with individuals living with CKD in Ireland. The participants self-reported their mental health histories using the Hospital Anxiety and Depression scale (HADS) and the Short-Form (SF)-12 to assess health-related quality of life (HRQoL). Recruitment was completed ($n = 268$) via the Irish Kidney Association social media pages and three large Irish hospitals. Depression rates were marginally higher for those individuals receiving haemodialysis (HD) compared to those with a KT and individuals not receiving KRT. A lower HRQoL was associated with depression, anxiety, and having a mental health diagnosis. There is a necessity for routine screening to be applied in clinical practice for psychological distress, mental health difficulties, and suicide risk, along with a prioritisation of access to effective mental health services for individuals living with CKD. Similarly, to the recommendations by Kidney Care UK and the National Psychosocial Working Group (2022) there is a need for kidney care teams to be sufficiently resourced with mental healthcare professionals, including social workers, psychologists, and psychiatrists (Cogley et al. 2023a).

It is vital that the emotional perspectives of individuals with KD are not underestimated. In 2012, Jonathon Hope, a patient advocate living with CKD in the UK, identified the need for more action to support the reduction of mental health problems for those living with long-term conditions following the report from the UK Department of Health (2011) 'No health without mental health'. There was further identification of the need for a robust campaign to highlight more awareness among renal healthcare providers, individuals impacted and carers of the cause, prevalence, and frequency of KRT and its complications, including depression, anxiety, and poor coping mechanisms that individuals with KD can face along with a necessary recognition of the interrelationship between mental and physical health (Hope 2012). This report was subsequently protected into UK law in 2012 with positivity moving forward; so why then over 10 years later is there still a delay for parity that was assured with the need for mental health to be given the same significance as physical health? This must be a priority for all to develop services to meet the psychosocial needs of individuals living with KD (Arday 2022).

Many organisations and associations worldwide advocate on behalf of people living with KD and their partners, families, and caregivers at local, national, and international levels to enhance their voice, to promote prevention and initial detection and to recognise the heavy burden of KD and its impact on QoL along with improving life conditions. This includes, for example, the Irish Kidney Association, the Northern Ireland Kidney Patients Association, Kidney Care UK, European Kidney Health Alliance (EKHA), European Kidney Patients' Federation, the American Association of Kidney Patients (AAKP), the Kidney Foundation of Canada, and Kidney Health Australia.

The AAKP (2019) launched the Decade of the Kidney (2020–2030) as a global initiative to generate increased awareness and establish demands for those persons living with KD for long-delayed innovations in kidney care with their insights, experiences, and engagement along with their care choice crucial to these changes. The EKHA is working with the AAKP on this global initiative at a European Union (EU) level to devise a step-wise progressive method including a structural recognition of CKD in EU programmes and strategies, the advancement of an EU code for prevention and screening of CKD, enhancement of disease management along with promotion of transplantation and home therapies. Furthermore, the importance of engaging with EU policy makers to enhance the quality of care for persons living with the burden of KD is paramount. Adults living with KD must be actively engaged in kidney health policy and become successful partners in the perseverance of their care (AAKP 2019; Vanholder et al. 2021, 2022). Concurrently in the UK, people living with KD have contributed to a campaign for enhanced mental health provision by petitioning their political representatives (Kidney Research UK 2022) again highlighting the relevance of recognition by policy makers of KD and its impact on individuals' QoL.

There is a necessity for further research to examine KD amongst those with mental health problems and the impacts of KD on mental health (Kidney Research UK 2019). Kidney Research UK (2023) issued the most widespread review of the health economics of KD in the UK for more than 10 years. One of several evidence gaps highlighted when developing this report was the need for UK studies on the association between KD and mental health incorporating the influence of poor mental health on adherence to treatment.

In 2020, Kidney Care UK – together with expert voices from various professional groups that provide psychological, social, and counselling services to persons

with KD – formed a National Psychosocial Working Group. There was a recognition of the wide divergence in service delivery both anecdotally and evidence based. It was established that the development of this working group would be a positive and progressive step in inducing change and enhancing quality and access to these services throughout the UK (Loud 2022).

Kidney Care UK and the National Psychosocial Working Group (2022) released the report: 'Caring for people with kidney disease: psychosocial health – a manifesto for action' in 2022. This manifesto is a nationwide call to action for individuals living with KD, their families, friends, and healthcare teams to unite and insist upon equal access to the highest quality, timely and renal specialist psychosocial care. The term *psychosocial* used throughout this document indicates the complete span of psychological, psychiatric, and social care needs. Psychosocial care is regarded within this manifesto as a key component of person-centred care. It depicts the relevance of considering the broad array of determinants impacting emotional well-being (integrating biological, psychological, social, and environmental feature) and that there are a variety of useful interventions that are provided by a diversity of professionals comprising clinical, health and counselling psychologists, counsellors, psychotherapists, mental health nurses, psychiatrists, and social workers (Kidney Care UK and the National Psychosocial Working Group 2022; Coyne and Fretwell 2022).

This report makes the following 10 key recommendations for change so that people living with KD can live their lives with the greatest possible mental and physical health:

1. The psychosocial care needs of every person with KD must be assessed by renal specialists (co-located psychology, psychiatry, and social care professionals) using validated processes. These assessments should be conducted when the person is initially diagnosed; as their treatment changes or transitions, as they advance through the various stages of CKD; during times of distress and yearly screening. This should include psychosocial distress and cognitive impairment (dementia). Standard distress and cognitive screening should be included to recognise those who require additional support.
2. The appropriate psychosocial care should be provided for every person with KD and should completely support their level of need, as part of their regular National Health Service (NHS) care delivery.

3. A person's level of need should dictate the psychosocial interventions required. The use of a traffic light system should be contemplated where there is standardisation in the level of a person's psychosocial care, and these levels of care escalate in intensity in tandem with their needs. Some examples include if the person's disease is not currently advancing, or if they so far do not require dialysis, transplantation, or end-of-life care they could be referred for general counselling such as Improving Access to Psychological Therapies (IAPT). Enhanced or specialised renal specialist psychosocial care should be extended to specific groups of individuals.
4. There should be an integration of psychosocial care needs for care plans with persons living with KD (which are generated by their hospital kidney team), which should include simple, understandable information concerning their condition, what to anticipate from their diagnosis, symptoms to watch out for, and how to avail of interventions and support. These care plans should be co-produced between kidney teams and mental health teams for persons with severe mental illness (SMI), dementia, or learning disability. They should signpost external resources that are applicable to the individual's cultural or ethnic background and relevant to their local community. Outreach should be available for at-risk groups, especially for those from diverse ethnic, cultural, and socioeconomic backgrounds to comprehend more about their specific needs.
5. The psychosocial care needs of people with KD along with their physical health can be supported better through the new NHS integrated care systems. This will ensure various parts of this system are better combined. There is a need for enhanced associations amid renal specialist psychosocial services and NHS IAPT services, secondary mental health and social care services, primary care services, and the third sector.
6. Within other diseases including diabetes, cancer, and cystic fibrosis there are multidisciplinary team (MDT) clinics that organise annual reviews wherein physical and psychosocial issues are considered equally. Renal MDTs should combine renal specialist psychology, counselling, psychiatry, and social work to guarantee persons with KD have access to all the support they require to assist them manage their condition and the multifaceted connections between mental and physical health.
7. To support access and equality to psychosocial care, staffing levels should be monitored.
8. The importance of education for all renal staff concerning the mental health needs of persons with KD so that they know who and where to refer them and act as first responders. Whilst mental health staff should receive education concerning screening for KD and management for individuals living with dementia and SMI. Specialist nurses are educated to deliver lower-level psychosocial provision alongside specialist supervision in both diabetes and cancer services. Whilst there are many accredited diabetes educational programmes in the UK that deliver psychosocial modules.
9. There is considerable disparity nationally in accessing integrated psychosocial care. Hence there is a need to introduce and monitor minimum nationwide standards of psychosocial care so that there is equality in terms of access to care for every person living with KD irrespective of geographical location.
10. The success of psychosocial services in enhancing the health of persons with KD can be monitored through the creation of a dashboard. This is available with other long-term conditions within the NHS such as the Diabetes Transformation programme in London, wherein mental health screening is available on its dashboard. It must be determined by the national renal and mental health teams the number of individuals who are on both the renal and the SMI registers (Kidney Care UK and the National Psychosocial Working Group 2022).

The Centre for Mental Health and Kidney Research UK (2023) report 'Addressing the Mental Health Challenges of Life with Kidney Disease: The Case for Change' recommended that the NHS needs to invest in expanded and enhanced psychosocial support for individuals with CKD (and other long-term conditions). There should be a stepped care model of psychosocial support regularly accessible to everybody of all ages living with CKD in Integrated Care Boards in England and Health Boards in Scotland and Wales. Healthcare providers for renal therapy services should ensure that all their staff are: (1) trained, supported, and supervised to recognise the psychosocial needs of individuals with KD; (2) practice through

psychologically informed means; and (3) provide low-level support and refer rapidly onward when more intensive support is necessitated.

The psychosocial health of individuals with KD should be regularly assessed by renal services including these services asking patients routinely about the quality of psychosocial support they provide. There is a necessity for more investment from government into research on KD and mental health to advance comprehension and support the continual development of services.

COVID-19 AND KD

Coronavirus-2019 (COVID-19) pandemic impacted health-care globally (Divyaveer and Jha 2021). People with some preexisting medical conditions were identified as being an increased risk of COVID-19 (Antoun et al. 2021) especially for individuals with preexisting KD (Divyaveer and Jha 2021). A containment strategy was therefore developed early in COVID-19 to minimise potential exposure (Antoun et al. 2021). In the UK, for example, 70,000 persons with KD were regarded as clinically extremely vulnerable to COVID-19 and were subsequently recommended to *shield* at home for consecutive months from the outside world. However, those that required in-center haemodialysis (ICHD) had no option but to travel to their local dialysis unit three times per week, which was likely to have been a harrowing experience (Kidney Care UK and the National Psychosocial Working Group 2022). Sharp and Loud (2020) discussed the outcome of a patient survey ($n = 1200$) conducted by Kidney Care UK throughout the first wave of COVID-19. It established that over 4 out of 10 adults considered their mental health had been affected by COVID-19. Loud (2022) highlighted that COVID-19 and the applicable shielding advice exacerbated prevailing anxieties and made everything more difficult for those living with KD.

Antoun et al. (2021) conducted a qualitative study in the UK to examine how the influence of early COVID-19 shielding restrictions impacted individuals' physical activity (PA), well-being, and QoL whilst conducting home haemodialysis (HHD) ($n = 10$) or accessing ICHD ($n = 10$). It also examined these individuals' experience of an enhanced dependence on telemedicine within clinical care. The results indicated irrespective of dialysis modality (HHD or ICHD) that PA, well-being, and QoL along with medical care were all impacted throughout this period. Negative consequences to PA, well-being, QoL, and medical care were reported by individuals attending ICHD. Those individuals receiving HHD mainly reported feelings of minimal change or a positive effect on their daily lives. There was an overall

support by individuals receiving both dialysis modalities for the use of telemedicine and an increased use of digital health technologies within clinical care. Some of the HHD participants were already aware of MyRenal-Care® and were more familiar to remote medicine and feedback than those individuals receiving ICHD. The recommendations identify the necessity for more proactive care if individuals are requested to shield again, along with an enhanced awareness of both safe and suitable PA to assist with home-based PA and emotional well-being – for example, the use of the Kidney Beam platform (Mayes et al. 2021), which will be discussed later within this section on COVID-19.

McKeaveney et al. (2021) completed a mixed method study aimed at comprehending the effect of COVID-19 in individuals with kidney failure (KF) accessing HD ($n = 44$) through assessment of features of mental health distress and decreased well-being. The findings highlighted the psychological, social, and emotional distress faced by individuals throughout the pandemic. It identified an initial comprehension of the distinctive experiences within the UK of this patient population. Similar findings were established by Lee et al. (2020) in the United States (US) who outlined the psychosocial challenges of individuals living with KF and HD during COVID-19. Hao et al.'s (2021) cross-sectional survey highlighted that the occurrence of anxiety and depression symptoms increased throughout the pandemic amid individuals receiving maintenance HD ($n = 321$). This study recommended additional concentration on patients' psychology with an initiation of targeted interventions to ameliorate their anxiety and further enhance their QoL.

Overwhelmingly, there should be global health methods engaged to address psychosocial tension, especially for those receiving long-term HD and people with other long-term illnesses (Hao et al. 2021). Another cross-sectional survey ($n = 300$) in the US examined chronic conditions (CCs) (including that of CKD, cancer, chronic obstructive pulmonary disease (COPD), drug abuse/ substance abuse and stroke) and the role of COVID-19 on patient activation and health locus of control (HLOC). More than 50% of the respondents identified COVID-19-associated anxiety or distress concerning managing their CCs. These respondents had lower patient activation and external HLOC in contrast to those respondents not impacted by COVID-19 associated anxiety or distress. The findings identified a necessity throughout the COVID-19 pandemic to provide additional support for those individuals confronting challenges in managing their CCs (Imeri et al. 2021).

Interestingly, a Dutch study ($n = 177$ with 75% of participants on ICHD; remainder accessing home dialysis or home therapies highlighted that COVID-19 did not appear to affect their mental health. Suggestions put forward include that these individuals may be better able to adapt to the pandemic as they have high resilience and are not as impacted by social distancing processes (Bonenkamp et al. 2021).

Porteny et al. (2022) conducted interviews with older individuals with advanced CKD ($n = 39$), their care partners ($n = 17$), nephrologists ($n = 17$), and physician assistants ($n = 3$) from four kidney centres throughout the US. This qualitative study wished to comprehend how shared decision-making for kidney treatment decisions was affected by the uncertainty of COVID-19 pandemic and how this can provide insights for sustaining shared decision-making throughout COVID-19 and future public health emergencies. The findings identify that shared decision-making was impacted by the vulnerability of older adults to COVID-19. Clinicians should promote and encourage conversations with individuals who wish to talk about COVID-19 with a priority on safety and QoL, including the hazards of COVID-19 and its impact on therapy options. These conversations should address all options including that of conservative management (CM) and integrate advanced care planning. Telemedicine was recognised by the participants as a convenient form of care and provided care partners the capacity to partake in clinical engagements when in-person care was limited. The openness identified towards telemedicine may also indicate a readiness to participate with other virtual tools such as web-based decision aids that could enable ensuing shared decision-making conversations for older adults with CKD. Clinicians could offer a pre-visit impartial description of therapy options with applicable advantages and disadvantages – for example, impact on prognosis and the role of the older adult's preferences and therapy choices (Porteny et al. 2022; Ladin et al. 2021). There is a need, however, moving forward for both investment in technology and telehealth training for populations who require it the most, including that of older adults (Ladin et al. 2021).

Long COVID refers to the disability and disease experienced by many individuals who survived the acute phase of COVID-19. There remain no systems that facilitate the assessment of the toll of long COVID and its myriad complications, including KD following the COVID-19 pandemic. This disparity needs to be urgently addressed and thus governments and health systems must develop adequate data systems that can encapsulate this missing

information. These data will be fundamental to inform health system planning for post-COVID-19 care (Al-Aly et al. 2023). Goodman et al. (2023) conducted a survey to identify associations between self-reported Long COVID and worse mental health within a population-based sample ($n = 9500$) in the US. Long COVID was described as reporting any present symptom that developed within 3 months of a confirmed positive COVID-19 test that could not be clarified by another diagnosis. The questionnaire encompassed multiple items associated with symptomatic experience of COVID-19, daily functional challenges post COVID-19 diagnosis, mental health, and socio-economic factors. This study highlighted that individuals with Long COVID describe worse mental health outcomes – including higher depression, anxiety, post-traumatic stress disorder (PTSD), suicide ideation and lower life satisfaction. Further research is recommended in this area (Goodman et al. 2023).

There is an increased recognition of the strengthening of negative consequences on the kidney community in the aftermath of the COVID-19 pandemic. The burden on the health and well-being of those impacted by KD has been incalculable as the degree of natural disasters and other overwhelming events instigated by human activities intensifies. It has become internationally vital that there is readiness amid health systems which includes establishing a robust system that can dispense with the health needs of complete community throughout periods of unforeseen disturbances to standard care. The multifaceted medical needs of those who have KD are not gathered by systems handling catastrophes itself. They are usually heightened by an acute escalation in burden via new patients because of the crisis itself. Disturbances in kidney care because of unforeseen consequences are becoming more predominant and expected to intensify in the years to come. Thus, it is only fitting that the World Kidney Day (WKD) theme in 2023 concentrate on *Kidney Health for All: preparedness for the unexpected in supporting the vulnerable* (Hsaio et al. 2023, on behalf of the WKD Steering Committee).

The EKHA (2021) led a call to action that recommends several areas to be addressed in view of the COVID-19 pandemic. It highlights the heavy burden of CKD in Europe and advocates the necessity for urgent action including to enhance efforts on CKD prevention such as cohesive approaches and targeted investments at both national and EU levels to eliminate core lifestyle-associated risk factors for major CCs including CKD. There needs to be a cohesive approach to address the considerable lack of equivalent and supportable data on chronic disease frequency in the EU. KT should be promoted whenever feasible and suitable as it

remains the best therapy option for KF. There were missed opportunities for KT because of COVID-19 with a reduction in donation and transplant activities (EKHA 2021).

The use of telehealth has altered the practice of healthcare throughout COVID-19 (Lew et al. 2021). A paradigm shift is urgently required towards home therapies and telehealth to better react to individuals living with KD in both the short and long term. The use of home dialysis modalities should be promoted that has shown to enhance the QoL of individuals, along with reducing their necessity to visit hospitals, thereby minimising exposure to COVID-19 and maintaining care. COVID-19 highlighted that there are extensive choices for 'healthcare from a distance' – specifically, individuals living with peritoneal dialysis (PD) (EKHA 2021). The uptake of digital technology and 'eHealth' interventions should be promoted which could provide areas of standard and improved CKD care (Mayes et al. 2021). This includes the use of remote management for individuals that can enhance patient empowerment. Other digital tools include telemedicine consultation, artificial intelligence assistants, and mhealth apps (EKHA 2021).

A 6-month prospective feasibility project supported by Kidney Research UK was conducted to allow rapid design, delivery, and evaluation of Kidney Beam during the COVID-19 pandemic. The Kidney Beam programme (<https://beamfeelgood.com/home>) is context specific, theory-informed intervention that was constructed to promote digitally delivered PA and emotional well-being self-management in adults living with CKD, as directed by the Behaviour Change Wheel (Michie et al. 2014). The use of social media promoted this platform with no extra technical or clinical support presented. The multidimensional digital intervention bundle was composed of online live and on-demand exercise training videos, careful meticulous selection of healthcare professionals (HCPs), and patient champions, use of email feedback and action planning, and online educational videos and blogs. Overall, 959 adults signed up to utilise the platform within the 6-month time frame; 276 participants completed the voluntary survey at baseline whilst 85 participants at 6 months completed the follow-up survey. In addition, 96% of participants surveyed would recommend Kidney Beam, with the major reported benefit being that the intervention was kidney-specific and provided by specialist kidney HCPs. Although there are recognised challenges around digital and health literacy, this digital self-management programme appealed to 736 participants living with CKD to sign up to the platform. A randomised controlled wait-list trial is in progress to evaluate the feasibility, clinical value, and cost-effectiveness of the Kidney Beam programme delivered as part of kidney care (Mayes et al. 2021).

HEALTH INEQUALITIES IN KIDNEY DISEASE

The theme for WKD 2020 concentrated on preventative measures in CKD along with highlighting inequalities in kidney care delivery worldwide (Li et al. 2020). COVID-19 highlighted the health impacts of long-lasting social inequalities, and that susceptibility to disease is shaped by conditions such as labour market structures and absence of social protection; for example, adults working in adverse conditions have inadequate access to sick leave and healthcare services and usually low earnings (Paremoer et al. 2021). This results in inability to manage to pay for adequate quality food, water, sanitation, and housing. Individuals may be reluctant to quarantine when they have COVID-19 because they cannot afford to lose wages and cannot work from home (BMJ 2021). These conditions interconnect with numerous factors comprising ethnicity, migrant status, class, and gender, to impact which population clusters are most compromised to COVID-19 infection (Paremoer et al. 2021).

The inequities gap in kidney care widened even more because of COVID-19 in low and lower-middle-income countries (LLMICs), which demonstrated an essential need for a global approach to care (Tannor et al. 2022). The International Society of Nephrology and the Dialysis Outcome and Practice Pattern (ISN-DOPPS) survey emphasised the significant inequalities in both screening and diagnosis of COVID-19 in individuals receiving HD in LLMICs throughout COVID-19, which related to a higher increased mortality (Tannor et al. 2021). The COVID-19 pandemic highlighted the many challenges that people living with KD faced. It must be acknowledged that a paucity of social and mental healthcare as well as a high necessity for these services remain a facet in kidney care. These preexisting inequalities remain after the COVID-19 pandemic (Kidney Care UK and the National Psychosocial Working Group 2022).

SOCIAL DEPRIVATION

CKD has a profound impact on the lives of individuals, their partners and families, and their financial stability with inadequate access to dialysis and a much lower possibility of KT in lower-income countries (Vanholder et al. 2021, 2022). Persons with KD may have to give up their work and receive benefits because of mounting frailty along with lengthy hospital appointments numerous times per week, possibly forcing them into poverty (Neukirchinger et al. 2018). They may rely on family members and caregivers or could have caring remits themselves. They could need home care as their housing

may not be suitable any longer. Therefore, they depend on social care services to address their needs for example domestic and personal care home support, assistance with taking medications, home therapies support, available transport systems, benefit and housing support, assistance with kidney diet and exercise schedules (Neukirchinger et al. 2018).

Kidney Care UK (2022a) conducted an online survey with 1042 participants (32% receiving dialysis; 32% transplanted; 25% had earlier stage KD; and 11% had KF but not receiving dialysis) to examine the cost-of-living crisis in the UK. The influence of cost of living escalates on mental and physical health is overwhelming. Nearly all the individuals surveyed (98%) are concerned about the increasing cost of living with the majority (60%) continually anxious about this. In this survey, 87% of respondents expressed these rises are influencing their mental health, with 15% highlighted that it is affecting them daily. The cost-of-living increases were also identified by 87% of adults as affecting their physical health, with 15% highlighted that it is also affecting them daily. It was identified the extra costs that derive with having a long-term condition with 87% of participants described that having CKD augmented their costs even prior to the cost-of-living crisis:

- *Higher heating costs.* Many individuals living with CKD can find it difficult to stay warm and thus require additional home heat.
- *Specialised diet.* Many living with CKD follow a special diet.
- *Transportation to and from numerous medical appointments.* For individuals receiving ICHD, this is three-times-per-week round trips.
- *Equipment needed for home therapies.* The expenditure of operating medical equipment in the home can add over £1,000 yearly to energy bills (Kidney Care UK 2022a).

Home dialysis regardless of region often results in at least some cost burden being transferred to individuals and their family members. Some countries (Australia, Canada, and New Zealand) provide local reimbursement policies to individuals receiving home dialysis for electricity, water, and waste disposal to balance these costs (Perl et al. 2023). There are reimbursement policies in some parts of the UK for dialysis travel and home dialysis costs. Unfortunately, variations in access to this repayment necessitates many individuals are subsidising some or all these expenses themselves (Kidney Care UK 2022a). Kidney Care UK (2023a) conducted another online survey with 1005 participants concerning their experiences of reimbursement. It

was established that 37% of participants on HHD advised that they are not receiving any reimbursement for energy expenses from their applicable NHS trust. These reimbursement payments vary greatly even amongst those conducting the same amount of dialysis, and 80% of individuals receiving home dialysis believe that the reimbursement amounts do not support all the expenditure their treatment incurs. Nearly 73% of individuals on HHD have been anxious about the expenses this winter with individuals (43%) on HHD considered returning to ICHD (Kidney Care UK 2023a).

CKD is one of many long-term conditions now established as diseases of social disadvantage (Norton and Eggers 2020). The probability for developing CKD and KF or end-stage kidney disease (ESKD) is compounded amid persons of lower socioeconomic status (SES). This increased threat is interceded by adverse social determinants of health for example limited access to healthy foods and transportation, unsafe areas to exercise, poor health literacy and numeracy, discrimination, reduced social support, inadequate housing quality and stability, insufficient paid sick leave, and absence of health insurance (Norton and Eggers 2020). These adverse social determinants generate impediments to health-promoting behaviours and lifestyles and minimise healthcare access, increase environmental exposure, and increase stress and allostatic load. Allostatic load is the capacity of the body to sustain physiologic homeostasis in reaction to physical and psychological needs of stress through suitably coordinated reactions in the endocrine, cardiovascular, metabolic, immune, and autonomic systems in the body. These factors additionally may escalate allostatic load-recurrent stress responses or increased activity of systems to sustain allostasis depending on the individuals' ability to cope with the stressors (Norton and Eggers 2020).

These adverse social determinants additionally could have lifetime or even multigenerational effects, through means of developmental programming or by stimulating epigenetic changes. These processes add to inadequate kidney outcomes directly and indirectly, through enhanced risk of underlying (e.g. diabetes, hypertension, and HIV) and complicating (e.g. depression) diseases (Norton and Eggers 2020). Smoking, obesity, and alcohol consumption are all lifestyle-associated risk factors that are also linked with socioeconomic deprivation (Guthrie and Bell 2019). These are some examples of lifestyle related risk factors that can all impact on kidney health and nurses play a vital role to both educate and empower adults to make informed choices concerning their well-being (Murphy and Byrne 2022a).

In developed countries like Australia, despite universal access to healthcare, the prevalence of ESKD

is considerably higher in less advantaged populations with a low SES and has a negative impact on younger dialysis patients' survival rates (Krishnasamy and Gray 2018). Nelson et al. (2020) suggests that the findings of the study by Krishnasamy and Gray (2018) outline a subtle interaction between the existence of nature as opposed to nurture factors. The social determinants of health play a pivotal role in the management of CKD not unlike environmental and genetic factors. It is necessary therefore to identify these factors in individuals and comprehend how they could be diminished to avoid the impediment of suitable disease management (Nelson et al. 2020).

Caskey et al. (2018) identified in their kidney health inequalities report (on behalf of Kidney Care UK) that health inequalities occur amongst people requiring KRT. Health inequalities are allied with variances in choice of or access to KRT modality – for example, social deprivation persists in being a risk factor for decreased use of home dialysis (such as the space needed to store dialysis supplies and equipment). These findings are consistent with a retrospective French study by Beaumier et al. (2022), which measured the association between social deprivation projected by the European Deprivation Index (EDI) and PD uptake to determine the possible mediators of this association. The data was collected using the Renal Epidemiology and Information Network (REIN) registry ($n = 9588$ with $n = 1116$ on PD). It established that social deprivation, measured with the EDI, was associated with lower prospects of PD 3 months after initiation of KRT. There was also an indirect outcome of the haemoglobin level at the start of dialysis, a proxy of pre-dialysis care, along with urgent start on PD uptake 3 months after the start of dialysis. This highlights that despite a universal healthcare system in France there are concerns around socially deprived individuals accessing healthcare services (Beaumier et al. 2022).

A person's age, ethnicity, sex, body mass index (BMI), and SES along with comorbidities are all regarded as inequalities as well as where the individual lives in terms of size and type of accommodation, the geographical location, along with the renal unit facilities that influence the KRT modalities. It has not been established if there is a causal relationship between inequalities and outcomes (including patient survival). There is a necessity for further research to address these issues and guarantee equitable outcomes for individuals living in the UK with ESKD (Caskey et al. 2018).

Kidney Research UK (2019) in their summary report upon 'Kidney Health Inequalities in the UK – an Agenda for Change' outlined that individuals from socially

deprived groups usually have poorer outcomes, including higher mortality rates, along with decreased levels of health literacy and education. They have associated risk factors for CKD, including, obesity, hypertension, and diabetes and because of their debility may tumble down, so to speak, the socioeconomic scale. There is a multifaceted interface between ethnicity and SES with individuals from Black, Asian, and minority ethnic backgrounds who are more likely to experience comorbidities associated with CKD and advance quicker towards KF as well as waiting longer for a KT. There is an increased prevalence of CKD in areas of higher social deprivation. Women are more likely to present with CKD and men are more likely to commence dialysis, but older persons are less likely to receive a KT. It can also be difficult to access dialysis services when living in rural settings (Kidney Research UK 2019).

The Chronic Renal Insufficiency Cohort (CRIC) study (currently 3,140 participants) is a continuing multicenter, observational study of diverse adults with moderate to severe CKD in the US. It established those individuals who depended on emergency department (ED) / urgent care as typical source of care were a vulnerable group in terms of reduced SES with a disproportionate number of persons from racial ethnic/ minority group with considerably lesser educational attainment and yearly income. They also had advanced comorbid condition burden and weaker blood pressure and glycaemic control. There was an association of an increased risk for hospitalisations and mortality in patients with CKD whose typical care is that of ED/ urgent care. There is a necessity therefore to better comprehend barriers and enable access to care for this high-risk group with the aim to enhance health outcomes and diminish costs (Toth-Manikowski et al. 2022).

FOOD AND FUEL BANKS

Individuals who are encouraged to adhere to a healthy renal diet may have trouble following diet recommendations if recommended foods are not physically or economically accessible (Puchulu et al. 2023). Kidney Care UK and the National Psychosocial Working Group (2022) highlighted that some individuals living with KD who have lost their jobs subsequently have insufficient and unattainable welfare support are therefore depending on food banks. However, with the ever-increasing costs in living crisis resulting in food insecurity, more people are turning to the use of social and community alternatives along with food and fuel banks. *Social and community shopping* is a term used to describe local schemes that

can help a persons' money go further when food shopping. These vary from nearby run supermarkets that provide surplus food, to community clubs that provide low-priced memberships in exchange for discounted food. There is a necessity for referral to food banks with individuals encouraged to get information of what is available to access in their locality. They should contact Kidney Care UK advocacy teams or local councils, healthcare workers, social workers, GP surgeries, local schools, and/ or local faith groups (Kidney Care UK 2022b).

Kidney Care UK (2022b) have collaborated with the Renal Nutrition Group of the British Dietetic Association and have established a list of foodbank foods, which are well suited to meet the dietary requirements of individuals living with KD. Individuals living with KD are also encouraged to contact their dieticians from their local kidney units if they are unsure of any of the foods provided at their local food banks. Within Europe, the European Food Banks Federation (2023) is a network of 351 food banks in 30 communities, reducing food insecurity and preventing food waste.

There are numerous people living in the UK (and beyond) who receive a limited income or are surviving on fixed state benefits who are confronted with a choice between feeding themselves (and their families) or heating their property. The concept of fuel banks work in a similar format to foodbanks; unfortunately, they are usually only accessible to those with a prepaid meter; local charitable support and charitable energy trusts are accessible for those who do not have a prepayment meter (Kidney Care UK 2022b).

STABLE HOUSING

Individuals who are homeless are likely to have more multifaceted health and social needs and numerous long-term physical and mental health conditions (Omerov et al. 2020). Stable housing is a basic human right, and unstable housing has a serious impact on human health, wellbeing, purpose, and output. The term unstable housing incorporates homelessness and housing insecurity. Housing insecurity represents housing that is of elevated cost, overcrowded, or hazardous. Housing along with other health-connected social needs may interrelate with recognised associations amongst poverty and structural inequalities that proliferate racial and ethnic disparities in KD. Unstable housing has been correlated with mortality, communicable and non-communicable diseases, acute care utilisation, an increased risk, and progression of KD. The relationship between housing and KD is possibly a

multifaceted interaction between individual and structural factors (Novick et al. 2022).

Henderson et al. (2022) conducted a qualitative descriptive study to depict the perceptions of adult men ($n = 16$) who were homeless related to their health and experiences accessing care. The findings identified three themes:

1. Men who are homeless experience prejudice all through their healthcare and interpersonal interactions.
2. Person-centred care is the best care.
3. The priorities of men who are homeless and care management are insufficient.

The housing requirements of individuals who are homeless are best considered by their health and social care needs. Their priorities must be taken on board to advance culturally congruent services that are suitable and effective care for this community (Henderson et al. 2022).

The conversations with individuals with KD concerning housing issues are achieved best using a non-judgemental and empathetic approach wherein the healthcare team previously has a positive relationship with the individual concerned. Several screening tools can be used, and the correct care plan should be initiated that contains aspects that are relevant for clinical care such as where medications are kept, access to a freezer, access to healthy foods, access to bathrooms, exposure to weather extremes, and physical welfare. Issues like using a short-acting diuretic may not be ideal in terms of ability to access bathrooms; therefore, a review of substitutes should be prescribed. A reduction of medications should be considered for example using longer-acting drugs is better over agents that necessitate multiple doses daily as there are challenges travelling and accessing pharmacies as well as storage of the applicable drugs. There should be close collaboration with different agencies to address impediments to care, including early intervention from social care and housing, including the use of flexible transportation to and from dialysis (as applicable) and emphasise patient safety. It is vital that there is an avoidance of the use of possibly stigmatising language in adults' care records (e.g. *non-compliant*) because of unstable housing, which could influence their dialysis placement or transplant candidature. Education should be provided to minimise environmental harm to those that are on dialysis in terms of protecting their vascular access and delivering medications throughout dialysis where feasible (Novick et al. 2022).

HEALTH LITERACY

Langham et al. (2022) on behalf of the WKD Steering Committee outlined the continuing high burden of KD and continuing global inequalities concerning kidney care. The theme of WKD in 2022 was that of advocating *Kidney Health for All*, the difficult concept of bridging the well-established gap in the global comprehension of KD and its health literacy. Centers for Disease Control and Prevention (CDC) (2020) identifies health literacy (HL) as both personal health literacy and organisational health literacy. HL is regarded as the degree to which individuals and organisations have – or equally facilitate individuals to have the capacity to discover, comprehend, and use information and services to impart health-related decisions and actions for themselves and others. These revised definitions highlight individuals' capacity to use health information rather than just comprehend same. It concentrates on the capacity to make 'well-informed' choices instead of "appropriate" ones. It recognises the responsibility that organisations must address HL. It integrates a public health perspective acknowledging within the organisational definition that HL is associated to health equity, which is achievement of the maximum level of health for all individuals (CDC 2020).

HL should not be regarded as an individuals' deficit, instead enhancing HL rests mainly with healthcare providers communicating and educating successfully in co-developed collaboration with those with KD. HL provides the essential for kidney policy makers to change organisations to a culture that positions the individual at the focus of healthcare. The advancing capacity of and access to technology allows new opportunities to improve education and recognition of KD for every stakeholder. The developments in telecommunication, including social media platforms used to improve both individuals' and healthcare providers' education. Kidney communities endeavour to avert KD and facilitate living well with KD through engagement and supporting kidney health-focussed policy making, community health planning, and HL approaches for all (Langham et al. 2022).

Unfortunately, the characteristics of individuals who tend to have lower digital literacy and access are similar, as those who are marginalised by established health inequalities – namely, lower SES, advancing age, minority ethnic background, and lesser educational accomplishment. To develop and apply digital health interventions effectively, it is vital not to ignore the necessity to develop eHealth literacy to enhance access for marginalised groups additionally to advancing tools to facilitate access

for those with established health inequalities. This is particularly significant for older individuals with CKD and those from minority backgrounds (Graham-Brown et al. 2022).

Around 25% of individuals with KD have low HL, particularly among those with low SES and non-White ethnicity (Taylor et al. 2017). It estimated also that 14–32% of individuals receiving dialysis have low HL (Cavanaugh et al. 2010). HL is specifically important for individuals with KD because of intricacy of self-care. Lameire and Vanholder (2020) discussed the impact of lower HL on the spectrum of kidney care (CKD, dialysis, and transplantation) with reduced medical and therapeutic adherence consequently. In CKD, lower HL is also associated with additional cardiovascular complications and a hastier progression of KF; whilst in dialysis it is related to additional uncontrolled hypervolaemia and lesser uptake of home therapies or home dialysis. There is also less pre-emptive/live donation in transplantation because of lower HL (Lameire and Vanholder 2020).

Boonstra et al. (2021) conducted a systematic review to distinguish favourable intervention targets and strategies for HL problems in individuals with KD. Individuals with lower HL have decreased knowledge or lesser capacity to modify behaviour. There is a necessity for customised interventions specially to support the KT process and smoking cessation to enhance the outcomes of individuals with lower HL. This review identified a limited amount of well-controlled studies on the influence of HL in Europe on the consequence of care in adults with non-dialysed CKD. Most studies originated from the US. It also highlighted studies on the influence of the assorted European healthcare systems on the level of HL in KD as paralleled with other regions. Interventions that target the capabilities of healthcare professionals were totally lacking. There is a need for more support of individuals by healthcare organisations with lower HL to prevent adverse health outcomes. Although the best intervention strategies remain underexplored, the use of web-based education was hopeful for enhancing knowledge and behaviours (Boonstra et al. 2021; Lameire and Vanholder 2020).

CKD AND MENTAL ILLNESS

There is a three directional association with CKD, mental illness, and its impact. CKD can influence an individual's mental health, whilst mental illness, or pre-prevailing trauma, can lead circuitously to KF. There are poorer outcomes with KD for those with co-prevailing mental illness, dementia, or learning disabilities or intellectual

disabilities (ID) and/or neurodevelopmental conditions (Gerogianni 2019; Turpin 2018; Seekles et al. 2020; Van Alphen et al. 2021; Whitney et al. 2020; Kidney Care UK and the National Psychosocial Working Group 2022, Zisman-Ilani et al. 2022). Persons with a learning disability are at enhanced risk of mental illness with some studies indicate the degree of mental health difficulties is up to twice that of the general population (Mencap 2022).

Individuals with learning disabilities or ID and/or neurodevelopmental conditions often contend with mental health professionals who receive minimal training concerning the needs of this population and related options for treatment and support. Greater emphasis should be provided for early and accurate diagnosis and non-pharmacological interventions to promote mental health among this population (Zisman-Ilani et al. 2022). There has been an association with higher rates of developing KD for those individuals with pre-established trauma or mental illness with increased rates of mortality than the general population. Examples include adults who have experienced adversative childhood incorporating emotional abandonment, sexual abuse, and residing with a caregiver with mental illness (Ozieh et al. 2020).

CKD AND SEVERE MENTAL ILLNESS

Iwagami et al. (2018) maintains that there is a high prevalence of SMI (including schizophrenia, bipolar disorder, and other non-organic psychotic illnesses) amid persons with CKD and those receiving dialysis. In the US, Wilk et al. (2022) identified that individuals with SMI encompass over 7% of everyone with KD, but this figure is not entirely measured in the UK. There are a multitude of complex rationales as to why persons with SMI have a shorter life expectancy by about 15 years as compared to the general population such as misdiagnosis and diminished access to care (Chang et al. 2011). Siddiqi et al. (2017) identify that persons living with SMI face elevated rates of long-term conditions and unfortunately can die 15–20 years earlier than persons who do not have SMI. This occurrence is known as the *mortality gap*. The indicators of various mental illnesses could impact the individuals' capacity to self-manage, comprehend, or even consider the necessity for the therapy for example an individual with delusions may refuse dialysis as they trust they can treat themselves without the need for medical involvement (Turpin 2018).

Van Alphen et al. (2021) outlined that certain psychiatric drugs used for the treatment of bipolar affective disorder (lithium) and schizophrenia (antipsychotics) could lead to diabetes and/ or KD. It was established in the UK

primary care that individuals with SMI had a greater incidence of CKD compared to the general population. This was marked in adults with a history of lithium prescription. However, there was also an increase in likelihood of CKD even with adults not prescribed lithium and following modification for variances in established risk factors for CKD. Individuals with SMI additionally had an increased incidence of KRT and were more likely to be receiving HD as their modality than persons without SMI on KRT (Iwagami et al. 2018).

Cogley et al. (2022) identified in their literature review concerning SMI and CKD that there is a deficit of published evidence concerning the rates of SMI in individuals with CKD as compared to the high documented prevalence of mental health problems such as depression and anxiety in the CKD population. There are additionally adverse health outcomes including increased mortality rates and increased rates of hospitalisations for adults living with SMI and CKD. This review indicated that individuals with SMI access substandard kidney care, less appointments with kidney care specialists, and reduced likelihood in obtaining a KT. The suggestions proposed identified the relevance of education for kidney healthcare teams concerning the needs of individuals with SMI through close collaboration with psychiatry. There is a necessity for additional research examining the incidences of SMI in individuals with CKD along with the impediments and facilitators to efficient care within this population. It is essential to enhance health outcomes for those living with SMI and CKD (Cogley et al. 2022).

Carswell et al. (2023) conducted a scoping review with available evidence highlighted that there is an increased risk of CKD amid individuals who have SMI, that individuals with SMI have worse clinical outcomes from CKD, and that they are not obtaining specialist kidney care to the same extent as individuals without SMI. This scoping review also identified a lack of high-quality research concentrating on co-existing SMI and CKD. There is specifically a major gap in qualitative research. This is prevalent in addressing the related care pathways for individuals with SMI and CKD and how this is observed and administered in primary or secondary care mental health services along with how this compares to other long-term conditions related with SMI like diabetes, COPD, and CVD. There is a necessity to conduct further research and close the mortality gap (Carswell et al. 2023).

A recent Irish qualitative study using semi structured interviews was conducted to explore the barriers and facilitators to effective kidney care for adults with severe mental health difficulties (SMHDs) and how care

may be enhanced for this cohort. The participants were recruited through the Irish Kidney Association and three Dublin-based hospitals with ($n = 8$) mental and ($n = 14$) physical HCPs; all had expertise working with adults with KD and co-existing SMHDs. The results indicate that many individuals with SMHDs need further support to access kidney care because of challenges with their mental state, difficulties with motivation and organisation, cognitive difficulties, or anxiety and suspicion of the healthcare system. The participants' narratives identified that it is challenging to support the additional needs of individuals with SMHDs because of the division of physical and mental healthcare, merged with under-resourcing and understaffing. The lack of mental health training for renal HCPs influences their confidence in their capacity to deliver care to individuals with SMHDs. The findings also suggest that system-wide stigma to adults with SMHDs in healthcare adds to poorer outcomes for this community. This can often make it challenging for renal healthcare settings to meet the comprehensive range of needs of individuals with SMHDs and KD (Cogley et al. 2023b).

This study by Cogley et al. (2023b) highlighted that despite these recognised barriers, with sufficient social, community, and hospital support that adults with SMHDs and KD can have positive outcomes, even in the setting of substantial impairments and intricate presentations. There were a number of suggestions for enhancement in care for adults with SMHDs, including cohesive physical and mental healthcare. Assuming a *whole person* individualised approach to addressing the interface between mental health and KD. There should be MDT team-based care encompassing clinical nurse specialists, social work, psychology, and psychiatry within renal healthcare departments. There needs to be both communication and coordination amid renal and mental healthcare providers to enable safe and effective kidney care for adults with SMHDs. There is a need for further research in this area to inform the provision of care for this community. This study did not explore the perspectives of individuals with SMHDs and KD and their families and caregivers but concentrated solely on the perspectives of HCPs (Cogley et al. 2023b).

COGNITIVE IMPAIRMENT

Cognitive impairment is independently related to KD and increases in incidence with deteriorating kidney function. It is up to three times more prevalent and can appear at a younger age at the point wherein KRT needed. Cognitive interfaces of KD are not a new concept with long

established historical descriptions of uraemic encephalopathy and professed *dialysis dementia* to the current identification of cognitive impairment in those undertaking KRT. There are a multitude of suggested processes influence this burden including advanced vascular aging, substantial multi-morbidity, mood, and sleep disorders are frequent along with disease-specific consequences of uraemic toxins, chronic inflammation, and the impact of dialysis itself (Crowe et al. 2021). Both dementia and KD have shared risk factors such as diabetes, hypertension, and hypercholesterolemia – hence another rationale for increased rates of dementia in individuals with KD (Iyasere et al. 2017).

The influence of cognitive impairment on people living with KD is immense extending from escalated hospitalisation and mortality to reduced QoL and altered decision-making (Crowe et al. 2021). A meta-analysis aimed to evaluate cognitive function in PD as opposed to individuals living with HD outlined that persons receiving PD are less likely to have a reduced decline in cognitive function contrasted to those who are receiving HD (Ali et al. 2021). There needs to be additional research such as the use of randomised control trials (RCTs) into the management decisions for persons where cognitive screening of KRT populations would bring to attention the considerable number of individuals with undetected cognitive impairment. There should be additional deliberation of processes considered to conserve native kidney function and whether this can influence the natural history of cognitive decline. The effect of pharmacological therapy used for dementia in the general population and for affective disorders that can influence cognitive function also needs to be established in the KRT population. There is a requirement to develop comparable study endpoints for cognitive impairment and a necessity for enhanced detection and recognition of cognitive impairment in individuals needing KRT as well as further research that involves patient-derived outcome measures (Crowe et al. 2021).

LESBIAN, GAY, BISEXUAL, TRANSGENDER, AND QUEER (LGBTQ+) COMMUNITIES

Individuals from the lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities experience social, economic, legal, health, and healthcare-associated disparities (Mohottige and Lunn 2019). LGBTQ+ individuals are at disparate risk of KD. They may not seek medical care due to the cost, refusal of care, job loss, concerns of discrimination, and harassment (National Kidney Foundation 2021). There can be considerable unbalanced

barriers to obtaining, high-quality healthcare such as screening for diabetes and hypertension, which could intensify risk of KD. There can be a fear of discrimination that could inhibit LGBTQ+ individuals from reviewing their social supports and possible donors involving same gender partners in evaluation of kidney transplantation (Mohottige and Lunn 2019). Leeies et al. (2023) conducted a scoping review to explore inequalities in organ and tissue donation and transplantation (OTDT) for sexual orientation and gender identity (SOGI) diverse persons globally. This scoping review established that this diverse population experienced discrimination globally with no published benefits of their identities in the OTDT systems. There were recommendations proposed to advance equality for SOGI diverse persons along with recognised disparities that can function as targets for activity moving into the future.

Mohottige and Lunn (2020) recommends that kidney care teams should instigate the following measures to improve care in LGBTQ + including when talking with individuals to use affirming language as well as promote tools to enhance care for LGBTQ + individuals across all clinical backgrounds. There is a need to advance inclusive engagement of individuals for example in research as well as advocacy for and the application of non-discrimination policies that specifically embrace gender identity, sex, and sexual orientation to safeguard all individuals. Collister et al. (2021) in a narrative review deliberated on the care of transgender individuals with CKD and what HCPs should be cognisant of when delivering their care. Adverse outcomes are prevalent in individuals who are transgender, including mental health, cardiovascular disease (CVD), malignancy, and mortality. There is a need for additional research, including the effect of being transgender on outcomes in individuals with KD.

QOL AND LIVING WELL WITH KIDNEY DISEASE

There is a need to target what is relevant to individuals across the age divide, by concentrating on their QoL, including both physical and mental health. This could be targeted to individuals where it is relevant in their lives when they are not receiving direct care. There is a need to prioritise treatment modalities such as self-care in satellite units, HHD, continuous ambulatory peritoneal dialysis (CAPD), automated peritoneal dialysis (APD) and pre-emptive transplantation, which provides individuals with improved control over their lives and enhances overall QoL, along with mental and physical well-being. There is a need to recognise that KF is a family concern as it can affect family members' and caregivers' mental

health, along with individuals with KD. It is important that everyone concerned is supported (Hope 2012). Raoofi et al. (2021) conducted a systematic review and meta-analysis examining the HRQoL and the determinants across adults who underwent HD and PD. There were useful strategies for HCPs recommended from the studies conducted concerning an extensive range of physical, mental, and environmental factors. This could enable HCPs to recognise the actual requirements of individuals undergoing dialysis and meet them in a suitable way. It also provided evidence-based information concerning the impacts of factors including age, BMI, length of illness, type of dialysis, and geographical area of residence on individuals' QoL, which can be used to plan an effective treatment strategy for individuals undergoing dialysis. The evaluation of QoL in individuals receiving dialysis can also impart appropriate information to confirm the efficiency of clinical interventions, evaluate the mental and emotional difficulties of the illness, and recognise the influence of a particular treatment strategy on an individual through evaluating the quality of care (Raoofi et al. 2021).

The overall and domain-specific QoL (pain, self-care, activity, mobility, anxiety/depression) was measured using the EuroQoL (5 dimension, 3 level) (EQ-5D-3L) tool with data accessed from a prospective multinational study ($n = 1696$) within 11 centers from Australia, New Zealand, Spain, and Canada. The participants were from across the spectrum of CKD from stages 3 to 5 ($n = 787$), dialysis ($n = 415$; 69.9% on HD and 30.1% on PD), as well as transplant recipients ($n = 494$) (Krishnan et al. 2020).

This study found overall a significant decrement in QoL across all spectrums of CKD. The most frequently affected three main domains were pain, anxiety/ depression, and mobility. Individuals receiving dialysis identified more difficulties in nearly all domains compared with individuals at CKD stages 3 to 5. A lower educational status, coexisting comorbidities (such as diabetes and CVD), and an absence of a partner were associated with decreased QoL in nearly all dimensions. The importance of comprehending these triad of factors will deliver beneficial ways of detecting those who are most at risk of poor QoL and outlining innovative social and medical interventions along with the resources to support them, which are of significance to this group of adults (Krishnan et al. 2020).

McKeaveney et al. (2023) conducted a cross-sectional study to examine QoL and other functional outcomes in individuals with advanced CKD using the Kidney Disease Quality of Life (KDQoL-36) tool. The participants consisted of two samples of older persons (> 60 years) either

having CM, ($n = 263$; CKD stage 4 $n = 188$; CKD stage 5 $n = 75$) or receiving ICHD ($n = 74$). The findings indicated that there was significant impact on QoL for individuals with CKD stage 5 receiving CM. However, there was also significant impact on QoL for those receiving ICHD because of the burden of therapy. The evidence would suggest from this study that the use of QoL tools could assist with clinical prognosis in advanced CKD along with ensuring specialist support is accessible for suitable management of individuals with CKD (McKeaveney et al. (2023).

Tong et al. (2020) highlighted the need to develop and use patient-centred terminology for kidney health to improve patient autonomy, satisfaction, and outcomes. When feasible, an example of this could be to use the term *kidney* instead of *renal* (Levey et al. 2021). Clearly, common nomenclatures could improve communications at all stages of treatment, encouraging greater comprehension of the burden of disease and patients' feelings concerning this. This could lead to more successful communication amid all key stakeholders (Levey et al. 2021). The National Institute for Health and Care Excellence (NICE) (2021) identifies the need to clarify any technical and medical terminology when communicating with patients throughout any consultations with HCPs and ideally use common, jargon-free language.

Despite the burden of living with CKD and its associated disruption and confinement with daily living and impacting on treatment satisfaction and clinical outcomes, there does appear to be limited enhancement in QoL over the past several decades for individuals living with CKD. There is growing acceptance of the necessity to recognise and focus on patient priorities, principles, and goals to progress research, practice, and policy (Tong et al. 2018). There is an increased use of patient-reported outcome measures (PROMs) as a vital means of measuring treatment results in the perspective of what is meaningful for individuals living with KD, including QoL (Locatelli and Del Vecchio 2023). The Standardised Outcomes in Nephrology (SONG) is an independent and global initiative that brings collectively patients, care providers, and HCPs in collaboration to determine core outcome domains and outcome measures across the range of KD for clinical trials and other types of research. The outcomes will be established based on the collective priorities of all relevant stakeholders. This will assist in ensuring that researchers convey outcomes that are significant and applicable to individuals with KD, their families and caregivers, their HCPs; and consequently, support decisions concerning treatment. Each SONG initiative is founded on the target group of patients, which is determined by the appropriate stage of

CKD/ therapy stage (1-5): SONG-CKD, SONG-HD, SONG-PD, SONG-Tx (kidney transplantation), children and adolescents (SONG-Kids) or diagnosis e.g., polycystic kidney disease SONG-PKD, glomerular disease SONG-GD (SONG 2017; 2023).

LIFE PARTICIPATION

The concept of life participation (LP) is more precise than the wider construct of QoL. It positions life priorities and values of those impacted by CKD and their families at the core of decision-making (Kalantar-Zadeh et al. 2021). LP is described as 'the ability to engage in meaningful activities of life, including but not limited to work, study, family responsibilities, travel, sport, social, and recreational activities' (Tong et al. 2018; Carter et al. 2020).

SONG studies within excess of 9000 patients from all spectrums of KD from over 70 countries along with family members and HCPs identified both children and adult participants assigned greater priority to symptoms and impact of KD on their lives, whereas HCPs assigned greater priority to mortality and hospitalisation (Carter et al. 2020; Hanson et al. 2020; Tong et al. 2018). These studies highlight how LP signifies the ability to live well with KD (Gonzalez et al. 2020). The participant priorities from these studies are identified in Figure 4.1 within the conceptual framework of living well with KD. Individuals – no matter what type of KD or stage of treatment they are at – wish to be able to live a normal life as possible, to live well and sustain their role and social function along with having a perception of control over their health and well-being (Kalantar-Zadeh et al. 2021).

'Living well with KD' was the theme for WKD 2021. The conception behind this theme was enhancing cognisance and education with the main aim of empowering persons with KD to oversee their treatment and continue active partakers in life (Kalantar-Zadeh et al. 2021; Rhee et al. 2022). There is a necessity for developing and implementing validated PROMs that may be used to assess and address aspects of LP in standard care. A conceptual framework was developed which concentrated on patient-centredness with a prominence on competent symptom management and LP (see Figure 4.1). Various self-care themes within this framework are applicable to individuals living with KD: patient activation, self-management, patient empowerment, patient engagement, patient-centred care, LP, and the use of a strengths-based approach to build resilience (Kalantar-Zadeh et al. 2021).

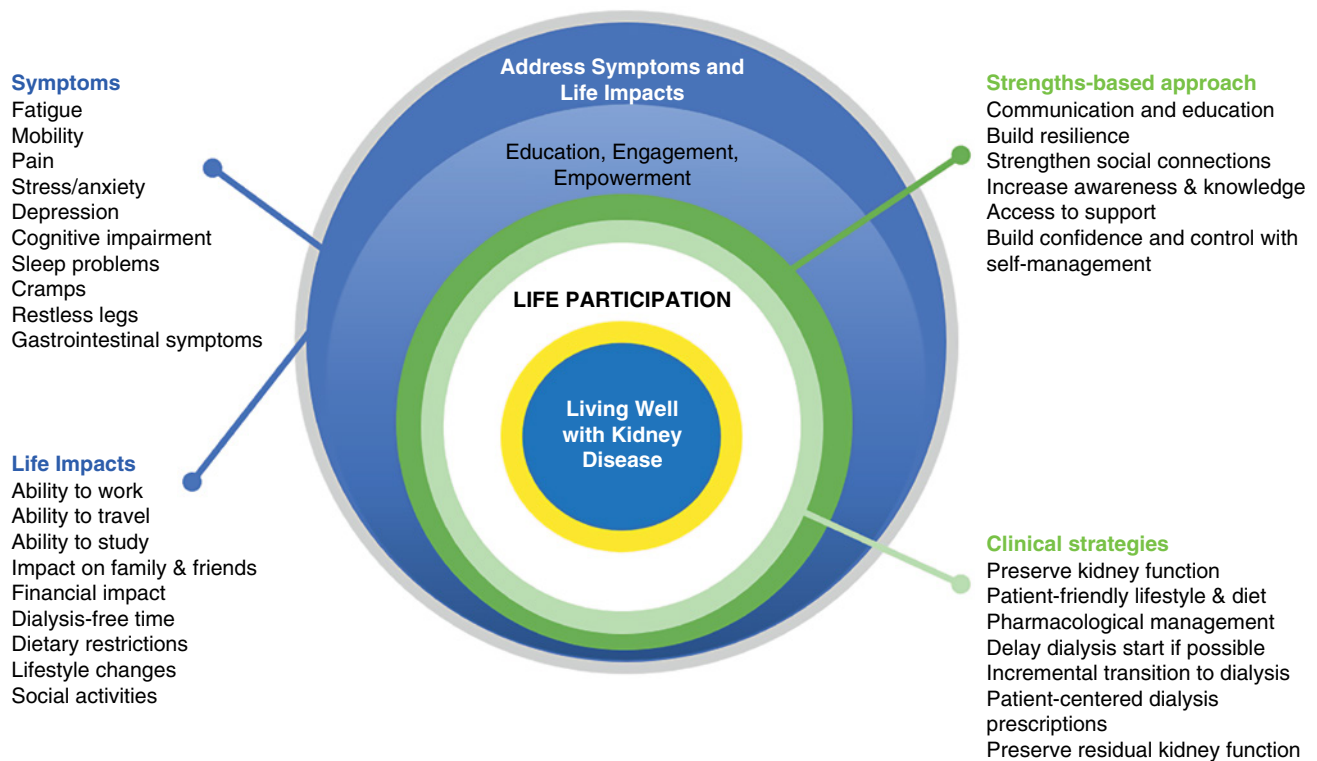


FIGURE 4.1 Conceptual framework of “Living Well with Kidney Disease” based on patient centeredness and empowering patient, with a focus on effective symptom management and life participation. (Kalantar-Zadeh et al. 2021 / Elsevier).

HCPs through an LP measure could comprehend and establish if adults with KD are on course to accomplish individualised goals and can provide the necessary resources to support their patients achieving them. There should be an LP measure available to manage right through the numerous transitions that individuals living with KD endure on their journey with KD. These transitions impart difficulties, distress, and challenges to confound before adjusting to the new changes in life. Thus, measuring LP is crucial to provide patient-centred quality care. The days of same kidney care and dialysis for everyone must be left in the past. Every patient should be treated as an individual with varied needs and goals, with their applicable treatment plan reflective of these variances. Individuals who are empowered are engaged in their care and with their healthcare team (Edwards and Manera 2022).

PATIENT ACTIVATION

Patient activation is swiftly becoming a main principle in patient-centred care and an essential part in the pursuit of value-based care (Hussein et al. 2022). Patient

activation involves the knowledge, skills, and confidence individuals have in managing their own long-term condition such as KD. The focus of person-centred care is enabling and empowering individuals to assume a more functional role in their well-being and healthcare. It is established as a key concept of self-management and is essential to support individuals to actively contribute to therapy choices, avert complications, and manage risk issues. It may enhance patient engagement and health outcomes by recognising an individuals’ activation level along with establishing interventions to enhance their activation (Lightfoot et al. 2022a). The promotion of patient activation in KD is progressively being prioritised. It has emerged as fundamental to KD legislative policy in the US with two kidney care models now contain patient activation as a quality metric. The patient activation measure (PAM) is identified as the patient-reported outcome (PRO) to apply when appraising in KD (Nair and Cavanaugh 2020).

A large survey conducted in the UK by Magadi et al. (2022) to investigate the association with PROs specifically symptom burden and HRQoL, to comprehend the affiliation between patient activation and outcomes.

Secondary data was used from the UK Renal Registry gathered as part of the National Transforming Participation (TP) – CKD service evaluation programme. The final sample recruited ($n = 3013$) were from 14 kidney units across England and had comparable demographic attributes to the overall CKD and KRT in the UK. The findings indicated a robust association between patient activation and HRQoL and symptom burden. Those individuals who are highly activated described a better HRQoL and a lower symptom burden. However, almost 50% of all participants with KD across various treatment modalities had low patient activation. Individuals receiving HD, those that are older, disadvantaged or from a non-White background were all allied to reduced levels of patient activation. Since patient activation reinforces effective and sustained self-management; its enhancement offers an appealing goal for interventions aiming to support and enable self-management behaviours. Further work recommended in this area includes the use of longitudinal studies, which should determine changes in activation over time to comprehend how individuals adjust from higher to lower activation, and how doing this, influences outcomes valued by the individual. The association between PAM levels and PROs indicates that methods targeting to enhance activation may have the capacity to influence areas of health and life which are valued by the individual in addition to HCPs and healthcare provider organisations. The use of resources, support, education, and advice with symptom management and physical rehabilitation may be necessary to assist self-management behaviours and enable the transition to higher activation states in this group (Magadi et al. 2022).

'My Kidneys & Me' is a theory-driven and evidence-based digital self-management programme for people with non-dialysis CKD. It is directed by an established process used for the successful development of the diabetes education program MyDESMOND (Diabetes Education and Self-Management for Ongoing and Newly Diagnosed Type 2 Diabetes). The planned outcomes of 'My Kidneys & Me' were to enhance and sustain effective self-management behaviours, incorporating PA and lifestyle, enhance knowledge, promote self-care skills, improve self-efficacy, and well-being. This was accomplished through the delivery of content and materials intended to increase CKD knowledge and patient activation, decrease health risks, manage symptoms, and enhance physical function. There were several theories and behaviour change techniques chosen to support the content and materials. Educational and behaviour change sessions, health trackers (e.g. observing blood pressure, symptoms, and exercise), goal-setting facets, and social

support forums are components developed within this programme. The systematic application of theory, empirical evidence, and practical perceptions in the co-development of 'My Kidneys & Me' content and materials were enabled by the application of the intervention mapping framework. The adopting and adapting of an established platform delivered a cost- and time-effective method for developing this digital intervention (Lightfoot et al. 2022b).

The efficacy of 'My Kidneys & Me' will be tested next in an RCT. The main aim of this study (Self-Management Intervention through Lifestyle Education for Kidney health (SMILE-K) is to assess the impact on patient activation levels. The secondary aims comprise evaluating the possibility of using such an intervention in this population and investigating patient experience of the actual programme. It is hypothesised that access to 'My Kidneys & Me' will enhance patient activation, contrasted with usual standard care, in adults living with CKD (Lightfoot et al. 2022c).

Individuals with low activation are less likely to identify early warnings of imminent complications or more rapid decline in their condition. They are also less motivated to act and are less likely to have knowledge of what to do should they decide to act regarding these warnings (Hussein et al. 2022). The use of a multifaceted model of care is recommended to enable patient activation that includes individuals receiving HD, their healthcare team, dialysis providers, and policymakers. (See Figure 4.2 for patient activation care intervention strategies.) The use of initiatives that aim to confront activation need to contemplate the challenges of including individuals with low activation, the intricacy of implementing a solution that takes on board the physical and emotional status of individuals receiving dialysis, and the contending pressures on both patients and staff time (Hussein et al. 2022).

INDIVIDUAL SYMPTOM MANAGEMENT

The Living Well with KD and Effective Symptom Management Consensus Conference (Rhee et al. 2022) provided a beneficial opportunity to assemble HCPs, advocates, individuals with KD, and their caregivers to discuss means to enable the best management of unfavourable symptoms in KD. It was acknowledged that it is necessary for members of the MDT to reframe their perspectives by connecting with individuals living with KD in describing their own individual values, likings, goals, and personal needs. A few management approaches were contemplated as central to provide

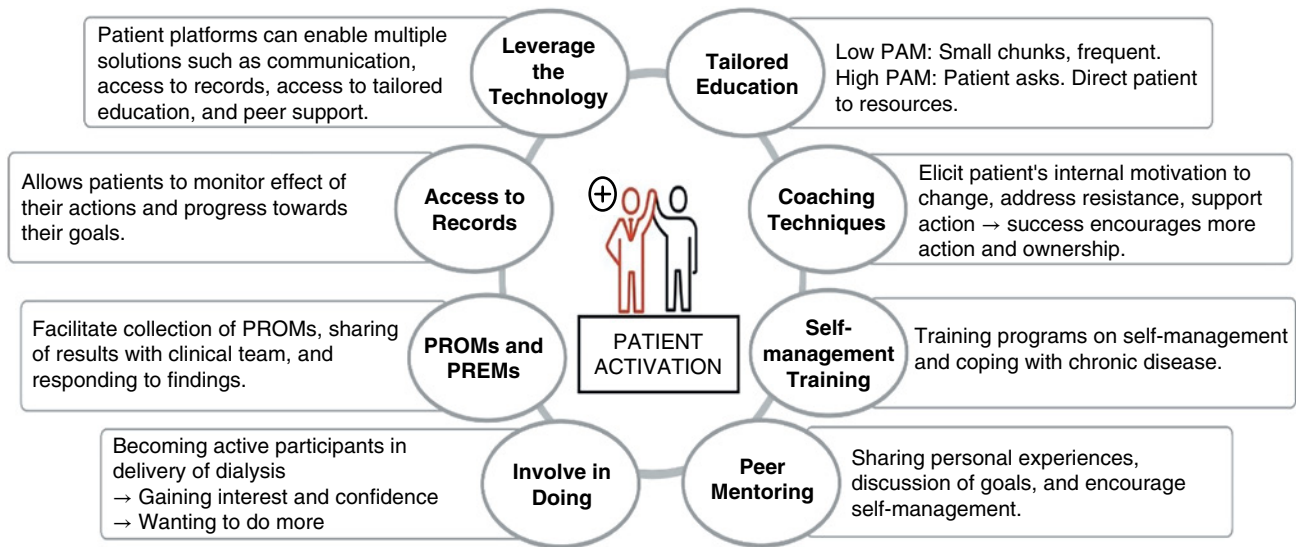


FIGURE 4.2 Patient activation care intervention strategies (Hussein et al. 2022 / Elsevier). Abbreviations: PAM, patient activation measure; PREM, patient-reported experience measure; PROM, patient-reported outcome measure.

personalised care, such as conservative and preservative management with the goal to prevent or postpone dialysis, incremental dialysis, and home dialysis or home therapies (Rhee et al. 2022).

Individuals with KD experience ‘a high burden of unpleasant symptoms that may be underrecognised, underdiagnosed, and undertreated’ (Rhee et al. 2022: 9). These symptoms include but are not limited to anxiety, depression, stress, cognitive impairment, fatigue, cramps, and sleep problems. It is crucial that individuals living with KD make continuing emotional adjustments throughout their journey with their long-term condition. This can be distressing and overwhelming, potentially leading to depression and anxiety. The emotional symptoms of KD are of equal relevance as physical symptoms, and a constructive and empathetic approach to addressing these should also be extended to partners, family members and caregivers. Person-centred communication is vital, including engaging and listening with the individual to build rapport. It must be kept in mind that it is unlikely that an individual will ever be ‘symptom free’. However, using open-ended questions such as asking what is concerning them and providing them the opportunity to talk whilst the nurse listens. Every patient contact should count towards a healthy lifestyle for the individual concerned (Murphy and Byrne 2022a). There must be an appreciation of what is most relevant to the individual living with KD and concentrate on each person’s values, goals, and personal needs. This could be relevant to moti-

vating them to engage optimal health instead of perhaps a clinical outcome measure such as recent laboratory results (Rhee et al. 2022).

Jones (2020) asserts that individuals cannot successfully communicate with their healthcare team about the difficulties they may have with their treatments as emotionally, they may experience phenomenon that they have never felt previously. It may be easier for an individual to communicate to their healthcare team whether a CKD-related symptom is based on emotional or physical conditions (or a mixture of both) if they are prepared as to what could happen. This could be provided through initial support with a first visit to a mental healthcare specialist when diagnosed (Jones 2020). Emotional preparation and consequently support is as relevant as educational preparation (Perl et al. 2023). There needs to be early identification and management of emotional symptoms by nurses and other members of the MDT that can incorporate pharmacological and non-pharmacological approaches. They need to be educated in management and treatment of emotional symptoms such as anxiety and depression using standardised approaches of screening (such as the Patient Health Questionnaire-9 (PHQ-9) and the Becks Depression Inventory (BDI) and diagnosing but being mindful of social and cultural background and any potential learning challenges with the individual concerned such as HL (Rhee et al. 2022).

Both individual engagement and self-help management are central to enhancing kidney health (Li et al. 2020). Individuals and their partners, family

members and caregivers need the necessary skills, knowledge and understanding to make informed decisions concerning their health, well-being, and life goals. Nurses and other members of the MDT play pivotal functions in empowering and promoting patient-centred care for individuals with KD. Nurses who engage in positive partnerships with patients, family members and caregivers can enable enhanced shared decision-making and self-care. Any decisions made should be decided in a timely manner – such as types of KRT, or CM (Murphy 2019; Murphy and Byrne 2022b). Every treatment option and their effects such as benefits and possible risks of treatment along with person-centred measures to competently manage symptoms should be discussed with the individual living with KD. They need to feel comfortable with the treatment and the applicable healthcare team. To reduce the impact the long-term condition has on their QoL, it is important to support treatment needs with the goals of the individual with KD. It is also important to recognise the wider impact of KD for the person and their partner, family members, and caregivers (Rhee et al. 2022). The choice of modality should be preference-sensitive, informed, and individualised centred on perceived QoL, life goals, and symptom burden. Using a shared decision-making process preferably individuals, their partners (or family members and caregivers as applicable), and their healthcare teams will decide together on the most suitable initial modality (De Jong et al. 2022). Home dialysis should not be restricted to individuals with high levels of activation and participation in self-care, as these can be enhanced with suitable education and support (Wilkie and Barnes 2019). However, there may be more options extensively accessible in higher-income regions, where KRT choices are less likely to be limited by economic factors. It is important to advise the individual who commences ICHD urgently that switching modality following clinical improvement is a possibility. Existing evidence indicates that ICHD, HHD, and PD are adequately similar in clinical outcomes to reinforce individualised and personal choice amid these options (Perl et al. 2023).

STRENGTHS-BASED APPROACH

The importance of a strengths-based approach and its applicability to CKD care was highlighted by the WKD Steering Committee. This method could empower individuals to live well with KD. It highlights collaborative approaches with individuals with KD in the growth, application, and appraisal of interventions for both practice and policy structures (Kalantar-Zadeh et al. 2021). The

participation of patients and their families and caregivers is crucial throughout this process and examples of this can be seen in the UK with co-production central to the ‘Think Kidneys’ programme wherein there is an equitable shared partnership approach (NHS England and the UKRR 2016; Gair et al. 2019). The strengths-based approach is a shift away from the biomedical model wherein there was a focus on pathology, challenges, and failures (Ibrahim et al. 2014). It recognises that individuals have strengths and capabilities to suppress the difficulties and problems confronted and necessitates partnership and nurturing their expectations, goals, interests, and values. The strengths-based approach embodies approaches to enable individual resilience, utilise social connections, enhance individual awareness, knowledge and understanding, enable access to support and determine confidence and control in self-management. There are suggested strategies provided that employ a strengths-based approach (see Table 4.1) (Kalantar-Zadeh et al. 2021).

Table 4.1 Suggested strategies for living well with CKD using a strengths-based approach (Kalantar-Zadeh et al. 2021 / Oxford University Press).

Strengths-based approach	Suggested Strategies
Build awareness and knowledge.	• Empower patients to ask questions and participate in shared decision-making about their care. • Provide information and support to facilitate lifestyle modification (e.g. information about diet). • Facilitate an understanding of CKD on various aspects of their lives including cognition. • Provide information about the different treatment modalities to include kidney transplantation and conservative management to empower patients to plan.
Build resilience.	• Provide patients with the knowledge of the impact of CKD on their quality of life at different stages (e.g. transitioning to dialysis). • Offer skills and resources to manage stress and functioning when facing challenges, impediments and trauma (e.g. associated with CKD or initiating of dialysis).
Harness social connections.	• Provide information and access to support groups with CKD and to learn coping strategies and get peer support.

(Continued)

Table 4.1 (Continued)

Strengths-based approach	Suggested Strategies
Facilitate access to support.	• Provide support to caregivers/families and provide them with information to access support groups. • Refer patients to other members of the interdisciplinary team (e.g. dietician, pharmacist, social worker, mental health professionals, occupational therapist). • Encourage patients to attend renal support groups. • Provide support to facilitate patients to engage in vital life activities (e.g. travel, work, attend family celebrations). This support may be in the form of facilitating haemodialysis for those who wish to go on holidays in their own county or beyond.
Establish confidence and control in self-management.	• Facilitate patients through open communication to identify their own concerns, goals, and priorities. • Provide approaches to prevent or address complications (e.g. infection). • Encourage patients to identify what works best for them, to voice their concerns, and collaborate to develop improved management approaches to enable them to feel better. • Support informed and shared decision-making (including dialysis, kidney transplantation, conservative management).

HAEMODIALYSIS

HD is the leading type of dialysis globally. During the last decade there has been considerable development in HD delivery and outcomes. However, individuals receiving HD still face poor QoL. Their PROs including fatigue, LP, depression, anxiety, sleep quality, cramps, and pain as well as financial and mortality, which are unsatisfactorily high. Furthermore, the outcomes of individuals receiving HD are monitored and reported inconsistently, and are substantially heterogeneous amid centres, regions, countries, and various sections of the population (Bello et al. 2022a).

Individuals receiving HD must remain at the centre of care delivery as vascular access is their lifeline to HD treatment. The renal healthcare team, especially the

nurse, play a vital role in the management of patients’ vascular access (Murphy 2014). The UKKA vascular access guideline for HD recommends specific access advice using simple information describing the comparative qualities of the range of vascular access for all adults and children expecting or undertaking a period of HD (Aitkin et al. 2023). They advocate the choice of vascular access as a patient decision taking on board personal individual characteristics and priorities and allowing sufficient time, supported by the MDT to reach a decision. Fistula formation is recommended for adults and children with appropriate anatomy and a probability of lengthy HD. It is suggested that it is suitable for any adult or child preparing for HD and expected to commence within 12 months to be referred for vascular access and if appropriate fistula formation, although timing for best vascular access is determined on the individual patient and institutional aspects (Aitkin et al. 2023).

NICE (2018) guidelines on renal replacement therapy and conservative management also recommend timely access to establish an arteriovenous fistula (AVF) about 6 months prior to the expected initiation of HD for this to mature. This timing considers the possibility of the first fistula failing or requiring additional interventions prior to use. These guidelines supported by expert commentary (Kharbanda et al. 2020 on behalf of the UKKA) also identify the importance of averting unplanned KRT by using temporary vascular access, which is related to adverse clinical outcomes.

Vascular access education is suitable for any stage of KD (Aitkin et al. 2023). However, all adults and children and their caregivers where suitable who are expected to need long-term HD should be educated in vascular access and vein preservation. This must be adapted to their personal situation and can be provided by various members of the MDT. In both adults and teenage children fistula formation is favoured over graft insertion apart from when it is necessary for premature cannulation or where anatomy at established sites is detrimental; in this case, it may be contemplated the use of a graft in adults (Atkins et al. 2023). Woo et al. (2022) strongly advocate the development and usage of a committed dialysis vascular access PRO, which will target issues that are relevant to individuals and result in a holistic vascular access enhancement pathway. It is vital that individuals with KF have a voice to vent their struggles relevant to the daily influence of sustaining a functional HD vascular access. There must be continual collaboration with all relevant stakeholders and priority provided to patients QoL and satisfaction (Woo et al. 2022).

Psychological and social well-being must be focussed on along with physical functioning to enhance adults QoL

receiving dialysis. Tommel et al. (2021) Dutch study investigated several cognitive-behavioural and social issues, with an emphasis on negative outcome anticipations that may be pertinent for HRQoL in adults with ESKD treated with both HD and PD. The findings established that individuals' feelings and thoughts concerning their disease such as helplessness and worrying, are considerably related to HRQoL and, consequently, could be of crucial importance in enhancing HRQoL. The use of embracing realistic and adaptive feelings and thoughts in addition to determining a strong social support system is advocated for individuals to achieve a life as normal and as contented as feasible, despite the unchangeable outcomes of their disease (Tommel et al. 2021).

Fernandez et al. (2022) scoping review aimed to depict how mental healthcare is provided to adults treated with dialysis in Canada. The findings have various repercussions for healthcare providers, dialysis stakeholders/ programmes and researchers. There was a lack of high-quality studies found especially RCTs examining the impact of mental health interventions for persons receiving dialysis in Canada. There needs to be a concentrated endeavour by stakeholders and researchers to minimise this disparity. There are distinctive challenges that need committed methods for individuals living with dialysis such as fluid and diet restrictions and therapy schedules, concurring disease symptomatology, and an increased risk of side effects with pharmacological methods. There is a necessity to devise clinical practice guidelines and clinical pathways in addressing mental health worries. There is a deficiency of mental health resources devised by kidney care organisations across Canada. These mental health resources are copious; however, they are usually directed toward the general adult population. Mental health interventions and resources should be individualised to manage the recognised needs of this group since individuals living with dialysis have distinctive stressors. There is a necessity to undertake studies to ascertain the quality of websites that deliver information on mental health for individuals with KD. There is a lack of regulation on the internet concerning the quality and reliability of these websites. The mental health associated websites with quality content should deliver evidence-based information and interventions (Fernandez et al. 2022).

There are many challenges for individuals living with HD to adhere to their treatment itself and various regimes associated with same including fluid and diet restrictions, and a high medication burden. Treatment adherence of adults that receive HD is crucial and is a complicated ongoing process. Non-adherence to treatment

could ensue in comorbidity, hospitalisation, mortality, and a worsening QoL (Ok and Kutlu 2021). The aim of a study by Ok and Kutlu (2021) (using a randomised controlled pre-test, post-test, and follow-up design) established the impact of motivational interviewing (MI) on adherence to treatment and QoL in individuals receiving maintenance HD. MI can be regarded as a collaborative, person-centred type of guidance to prompt and strengthen motivation for change with individuals (Miller and Rollnick 2009). It found the positive impact of MI on adherence to HD therapy using both objective and subjective factors. Furthermore, there was a statistical significance found in the mean scores pre and after the intervention concerning the deviations in pain, vivacity, social function, emotional role, and mental health in HRQoL. The use of MI could be regarded as an effective means in enhancing treatment adherences and QoL in individuals receiving HD. The main aim of patient-centred MI is to encourage and sustain behavioural change. This can be used as a suitable technique with treatment adherence challenges of adults receiving HD. However, nurses and other members of the healthcare teams who work with individuals receiving HD should use this method. However, they need to have specific MI training to employ interventions (Ok and Kutlu 2021).

Bazrafshan et al. (2023) conducted a descriptive correlational study ($n = 218$) with individuals receiving HD in Iran to exam the association between treatment adherence, procrastination, and complication in emotion regulation. The findings indicated that medication use, and attendance are associated to procrastination in these adults receiving HD. It also suggests that both the cause of KD and age were predictors of treatment adherence. To create any change, it may be better to concentrate on specific behaviours and not on general adherence. It is vital to recognise the issues impacting non-adherence of individuals receiving HD and again enhance their treatment adherence and QoL. There was a recommendation for additional studies in this area (Bazrafshan et al. 2023). A meta-analysis was conducted to evaluate the impacts of treatment adherence enhancement programmes on treatment adherence and secondary outcomes for adults on HD. There was a statistically significant impact of treatment adherence enhancement programmes for adults living with HD. The findings offer evidence-based data for improving programme efficacy when devising treatment adherence enhancement programmes for this cohort (Kim et al. 2022).

The UKKA clinical practice guideline on HD recommend intradialytic exercise as a therapy for improving physical functioning in adults without contraindications; this should be accessible in all units. Intradialytic exercise should be regarded as a means of enhancing individuals'

QoL and should be developed by suitably qualified staff (Ashby et al. 2019). The importance of PA and exercise is also recommended by the UKKA clinical practice guideline on exercise and lifestyle in CKD to enhance QoL including mental health across all spectrums of KD (Baker et al. 2021). Brys et al. (2020) conducted a study in Italy with adults receiving HD ($n = 37$) to monitor spontaneous daily physical activity (DPA) with motion devices and examine its association with fatigue and depressive symptoms. Both these symptoms are regarded as main obstacles to PA with individuals on HD. It is important to develop a better comprehension of their interconnection to progress successful therapies. It was established that spontaneous DPA is influenced by age instead of fatigue or mood (Brys et al. 2000). Ferreira et al. (2021) systematic review and meta-analysis also indicated the impacts of exercise interventions are effective in decreasing mood disorders such as depressive symptoms and anxiety.

Bayülgen and Gün (2022) conducted a systematic review to establish the impact of complementary and integrative therapies on fatigue in adults receiving HD. Acupressure, aromatherapy, reflexology, massage, and yoga practice have all been identified in the literature to be useful in diminishing pain and anxiety along with enhancing sleep quality. It is advocated that these practices be incorporated into standard clinical care of adults receiving HD. Zhang et al. (2023) conducted a meta-analysis concerning the use of aromatherapy for individuals receiving maintenance HD. They concluded that aromatherapy can be used as an innovative alternative and complementary treatment to enhance sleep quality and decrease fatigue and anxiety in this cohort. Its use, however, does not considerably lower AVF puncture pain. There is a necessity for high quality multicenter trials with large samples to further investigate the intervention impact of aromatherapy on problems linked with maintenance HD. There should be additional research conducted to explore the practice of aromatic massage and the impact of various oil types and dosing protocols, concentrations, types, and practices in aroma diffusion (Zhang et al. 2023). Matthews et al. (2021) conducted a non-randomised pilot study ($n = 20$) with individuals receiving ICHD in Northern Ireland to investigate the feasibility of providing intradialytic reflexology. It was identified that this intervention was feasible and well received. The outcomes of this study provide renal units with a greater insight of the possible value of reflexology, which could encourage more HCPs to outline the use of these complimentary therapies with their patients. The use of reflexology could be promoted as a non-pharmacological therapy along with the usual treatments and care delivery.

The impacts of mindfulness meditation on trait mindfulness, perceived stress, emotion regulation, and QoL in adults undergoing HD was examined using an experimental study in Kuwait. Mindfulness meditation is usually successful in enhancing health outcomes and could be used as a means of coping for people receiving HD to assist with stress management and health. This was demonstrated by the end of the intervention by a reduction in perceived stress and a rise in trait mindfulness, emotion regulation and QoL amid the individuals from the experimental group (Alhawatemeh et al. 2022). Wilson et al. (2022) discussed their impending study to support a novel service development project in collaboration with Kidney Care UK by employing the four-session compassionate mindful resilience (CMR) syllabus, devised by Mindfulness UK and ascertain its usefulness for individuals with stages 4–5 CKD or have obtained a KT. This study will examine the impact of the CMR syllabus on anxiety, depression, self-compassion, the ability to be mindful, well-being, and resilience using a quasi-experimental design. It will also explore using a qualitative approach with individuals and their mindfulness teacher factors impacting the feasibility, acceptability, and appropriateness of the intervention and their dedication to practice. It is anticipated that the consequence from this study will involve an evidence-based mindfulness and compassion syllabus to use with individuals with KD (Wilson et al. 2022).

Kidney Care UK (2023b) outlines the concept of emotional resilience which encourages individuals with KD to being open to their experiences (even the distressing ones), living in the now (mindfulness/noticing) and working on the values that matter most to them. They outline the use of an emotional resilience toolbox with six tools:

1. Accept that anxiety can impact on a person physically.
2. Reclaim control by concentrating on breathing with a technique provided.
3. Use an app to deliver some serene time such as music or a mindfulness app which may help with relaxing or with sleep.
4. Talk to someone; this could be a member of the healthcare team, a family member, a friend, or Kidney Care UK patient support and advocacy services.
5. Practise mindfulness.
6. Attempt to spend a set time to worry, as being worried can easily take over an individuals' every thought.

Individuals with KD are encouraged to make an ongoing commitment to apply these areas, which can build resilience and can assist them in managing the unavoidable struggles of living with a long-term health condition (Kidney Care UK 2023b).

Music intervention is a widely applied non-pharmacological therapy method or complimentary therapy. A systematic review and meta-analysis established that music intervention could partly enhance physical and emotional difficulties in adults undergoing HD. The substantial physical benefits of music intervention include impact on breathing, oxygen saturation levels, sleep quality, state anxiety, and stress, whilst music intervention has an average and beneficial impact on pulse rate, blood pressure readings, pain, and anxiety. There was a recommendation for further RCTs in this area (Yangöz and Özer 2022). Another systematic review and meta-analysis by Wu et al. (2021) found similar beneficial impacts of music-based interventions for reducing pain perception, heart rate, anxiety, and blood pressure. The use of these findings should be contemplated when devising best practice guidelines for the management of physical and psychological symptoms in individuals receiving HD. Soliva et al. (2022) conducted a prospective group randomised intervention study in Spain with adults on HD to establish if the intervention of classical music live and “in situ” throughout HD therapy impacts on their HRQoL. The findings indicated that the application of live music enhances their self-perceived QoL. It can be used as a significant therapeutic resource that acts as an adjuvant to kidney therapies as well as positively influencing the individuals’ well-being.

There is lack of evidence concerning the impacts of guided meditation (Yoganidra) on QoL among adults receiving maintenance HD. The use of guided meditation ensued in statistically significant enhancement in qualitative attributes of well-being including a level of happiness, eagerness, inspiration, vigour, attentiveness, cognisance, level of stability, self-confidence, self-reflection, clearer thoughts, in the intervention cohort of participants as determined by quantitative and qualitative methods (Vaishnav et al. 2022). There was a significant enhancement in stress levels as determined by perceived stress scale, KDQoL connected to burden and impact of KD, symptoms of KD, and complete KDQoL record. It is easy to instigate guided meditation and is effective in improving several aspects of QoL and well-being. It can be advocated for addition in standard care for improving QoL of individuals receiving maintenance HD (Vaishnav et al. 2022).

The Renal Arts Group (RAG) at Queen’s University Belfast was formed in 2016 as a partnership amid patients

with KD, caregivers, HCPs, academics, and artists to devise a programme of research with the goal of enhancing the physical and psychological QoL of those living with KD through the medium of the arts. The group goals are to provide a voice to individuals living with KD, enhance public engagement, and advance social impact through interdisciplinary collaboration amid academics, researchers, healthcare professionals, service users and policy makers (<https://www.qub.ac.uk/sites/renal-arts-group>).

As part of the Renal Arts Group agenda, Wilson et al. (2021) discussed an initiative to devise guidelines for implementing volunteer-led arts activities for adults receiving HD. The applicable research team in discussions with the local healthcare trust made the choice that trained volunteers would be well situated to assist the artist-in-residence work, whilst being able to devote extended periods of time with individuals to concentrate on skills development and endorse sustainability and engagement of the arts intervention. The original initiative in the guideline’s development was direct one-to-one bedside enablement of arts activities. This did not transpire because of the COVID-19 pandemic and the associated restrictions. The use of virtual volunteers reflects a flexible and responsive perspective were initiated in guidelines and can provide one-to-one support and encouragement for individuals by phone or online. It continues support for patients to sustain their art projects when non-healthcare workers were not in a position to attend the renal unit and throughout periods of limited access to the renal unit. The pandemic restrictions have relaxed considerably but the use of virtual volunteers may continue for the predictable future (Wilson et al. 2021).

Carswell et al. (2019) devised a person-centred complex arts-based intervention in Northern Ireland for individuals receiving HD utilising the arts in health development framework. Example of arts-based interventions include creative writing such as poetry or short stories or visual art activities. There is a lack of evidence on the efficacy of complex arts-based interventions for enhancing well-being, health, and QoL. A collaborative approach with service users, HCPs, and main stakeholders in developing evidence-based, arts-based interventions can assist deliver access to amply satisfactory, safe, and holistic care (Carswell et al. 2019). A process evaluation was conducted by the same authors (Carswell et al. 2021a) as part of a larger feasibility study to discover both acceptability and experiences of an intra-dialytic arts-based intervention. Both individuals on HD and HCPs identified the intervention as a positive effect on them with better communications with a more humanistic focus identified by the HCPs with individuals in terms of discussing issues surrounding the applicable arts that was

not associated with clinical issues such as patient disease. The acceptability of the delivery of a facilitator of an arts-based intervention who was not a professional artist was another main finding from this study. This use of arts-based interventions could offer benefits to the mental well-being of both patients and HCPs. There is a need for further studies in this area using high-end methodologies along with advancing other holistic interventions to attend the mental health and well-being of individuals with KD (Carswell et al. 2021a).

HOME DIALYSIS

Home dialysis modalities or home therapies encompass HHD and PD. These modalities are associated with enhanced individual autonomy along with individual satisfaction with treatment in comparison with ICHD. However, worldwide the rate of home dialysis use is poor. The rationales for this underutilisation depend on a variety of situations, including local resources, dialysis expenditures, access to healthcare, health system procedures, healthcare provider's partiality or preferences, cultural values, individual lifestyle worries, possible care-partner time, and financial difficulties (Perl et al. 2023). Ethier et al. (2020) and Castledine et al. (2013) identified other major factors that have been associated with reduced uptake of home dialysis, including male sex, older age, minority ethnicity, enhanced comorbidities burden, reduced SES, obesity, and close vicinity to dialysis centers. There may be more barriers to participating in decision-making and/or to being offered alternate modalities with patient subgroups encompassing indigenous populations, specific religious groups, displaced individuals, those with lower HL, language barriers, or cognitive impairment. Responsive strategies are required with these individuals. Both community and cultural experiences can impact individual choice, as some may feel embarrassed about being ill or that conversations about illness are not permitted. There are numerous resources realistically required for successful home dialysis comprising a safe and clean environment, access to technology, and in many instances, support from family or community (Perl et al. 2023).

There is an increased demand for dialysis in the older population given the enhanced numbers of older adults living with KD progressing to KF (Wu et al. 2022). A review was conducted to evaluate some of the main challenges encompassing the delivery of home dialysis to older adults and suggest possible solutions established on updated evidence to overcome these challenges. The first challenge is HCPs negative perceptions and pre-

conceived bias concerning the suitability of older adults for home dialysis. Solutions here involve education initiatives to enhance perception of the possibility and advantages of home dialysis for older adults, highlighting patient-important outcomes compared to survival as the best metric of 'success'. The second challenge is anxieties concerning the burden of therapy upon commencement of home dialysis. Proposed solutions include slowly introducing an incremental dose method for HD and PD. The concept of planning for the unplanned includes using buried PD catheters, urgent start PD, catheter, and single needle choices where suitable and creating transitional care units. Another challenge is that home dialysis-related complications can be more predominant in the older population with augmented frailty and co-morbidity condition. Solutions identified involve using an individualised, goal-based tactic in managing dialysis-associated problems, which is probably more intricate in older adults. The clinical frailty scores should be regularly measured to appraise degree of frailty versus motivation levels to continue home therapy. The final challenge is the concept of caregivers stress and burnout from the responsibility of caring for the older adult accessing receiving home dialysis. Solutions suggested are both patient and caregiver financial incentives. A realistic long-term care plan should be developed to assist caregivers with resources and personnel for recurring respite care, community nursing support, and re-education programmes (Wu et al. 2022).

HOME HAEMODIALYSIS

HHD should be available in all units in the UK as part of an inclusive KRT programme (Ashby et al. 2019). However, globally in numerous regions including several high-income areas, individuals facing KF have limited or no access to HHD (Perl et al. 2023). There should be an individualised person-centred approach to training individuals for HHD and their family members and caregivers as appropriate. The training method should include a specific set of competencies, which should match the learners' speed (Ashby et al. 2019). The choice of HHD like PD is mainly determined by the individual patient's decision and education.

There are major benefits for those who opt for HHD, such as the home background, amenable scheduling, dialysis intensity, reduced pill burden, and independence with nutrition and fluids. HHD should be deliberated and provided to all individuals considered appropriate (NICE 2018; Kharbanda et al. 2020). Funderup et al. (2021) aimed

to address how individuals continued to be involved in their treatment and care of their own health after an intervention on shared decision-making on dialysis choice. Those individuals who opted for home therapies had become more encompassed in their care delivery of their own health with support from both family members and HCPs influenced positively to this choice. Shared decision-making has the possibility to enhance self-management in persons with KD.

PERITONEAL DIALYSIS

PD remains an appealing, patient-centered type of KRT (Auguste and Bargman 2022). PD has definite advantages compared with HD, including the accessibility of home therapy, enhanced QoL, technical ease, better cost-effectiveness in many countries, and enhanced survival specifically in the first few years of commencing therapy (Bello et al. 2022b). The UK Renal Association clinical practice guideline on PD in adults and children acknowledge that the success of a PD programme is reliant on specialised nurses with relevant knowledge and skills in assessing and educating individuals for PD therapy, supervising treatment, and the appropriate resources to provide sustained community care (Woodrow et al. 2017). Radmore and Hyrkäs (2019) identified that the relationship between the PD nurse and individuals receiving PD is vital for meaningful outcomes. This collaboration is unique and develops over time. Nurses need to alter their educational matter and teaching style to best match the needs of individuals obtaining PD and more importantly let them feel supported and cared for to have a successful partnership working together.

Blake and Brown (2020) discuss the relevance of patient-centred care and shared decision-making for those who are approaching KF and need to make choices concerning modality therapies. Patient-centred care is required for those individuals' commencing dialysis as well as PD prescription and care delivery. It is vital to any decisions made concerning goals of care, transplantation, conservative care, and withdrawal of dialysis. It is also applicable as to how PD is delivered for example possibilities such as incremental PD. The concept of engagement, education and empowerment of patients are essential within shared decision-making which should be a standard value of care. A central focus of patient centred care in PD is PROs with individuals having the chance to relate any reported outcomes and obtain the relevant symptom evaluation and management. Whilst patient-reported experience of care is another vital measurement of how effective patient-centred care is in PD which could be assessed to enhance care delivery (Blake and Brown 2020).

It must be ensured that those individuals approaching KF who wish to opt for PD can learn about PD and have a meaningful opportunity to be treated with this therapy. The PD healthcare team must be mindful that these individuals can be worried, distressed, and disadvantaged and they should be supported appropriately. Patients must be provided with a choice as much as feasible whilst being educated regarding the PD prescription they obtain including decision between CAPD and APD, the choice where applicable of pursuing an incremental PD approach, and the choices they have concerning how their PD prescription could be adapted to improve clearance, fluid elimination and control of symptoms. The importance of education for persons doing PD including knowledge and understanding about their condition as well as prognosis and provided with the option to express their goals of care. They should be advised of their choice to stop dialysis and change to a palliative care route if they so request and should be assisted by the healthcare team if they make this decision (Blake and Brown 2020).

It is well acknowledged that the well-being of the individual on dialysis is relevant to many diverse factors with moving the focus from small solute clearance targets to what patients' need and their goals (Auguste and Bargman 2022; Brown et al. 2020). Brown et al. (2020) on behalf of the International Society for Peritoneal Dialysis (ISPD) outlined their recommendations on prescribing high-quality goal-directed PD. Dialysis is only one element of care impacting outcomes – including multimorbidity (symptoms, polypharmacy, reduced physical and cognitive function), age (reduced physical and cognitive function, frailty, dementia/ delirium), psychosocial (anxiety, depression, social support, money worries, diminished time for LP), and dialysis-associated symptoms (polypharmacy, reduced appetite, burden of dialysis) (Brown et al. 2020). These *goal-directed* guidelines focus on the individual doing the PD. There should be shared decision-making between the individual doing the PD and the healthcare team when prescribing PD. The purpose is to determine realistic care goals that uphold QoL for the individuals as much as feasible by facilitating them to meet their life goals and diminish symptoms and treatment burden whilst ensuring high-quality care is delivered. The PD prescription should take on board the needs and lifestyle consequences of the persons requiring treatment involving those of their partner, families, and caregivers', particularly if delivering care assistance along with the local country resources. The delivery of high-quality PD care can be ensured by using a number of assessments such as PROMs. These are a measure of how an individual conducting PD experiences life and their feeling of well-being.

It should take on board the individuals' symptoms, influence of the dialysis routine on their mental health, daily life, and social surroundings (Brown et al. 2020).

The SONG-PD initiative based on the shared priorities of all stakeholders aims to determine core outcome domains for trials in PD. The core outcomes domains of PD were that of LP, inclusion of PD-associated infection, CVD, mortality, and technique survival (avoid transfer to HD). The concept of LP was regarded as a central goal to PD. However, fatigue was acknowledged as a possibly debilitating symptom that may impair LP. Participants identified the use of less negative terms such as *PD failure* and instead a more positive framed alternatives such as *technique survival*. There is a necessity to establish a recognised measure for LP that is easy to process and appropriate to every patient incorporating those from low- and middle-income countries (Manera et al. 2019a, 2019b, 2020). A SONG-PD LP consensus workshop was conducted in 2020 with 56 participants (individuals receiving PD, caregivers, HCPs, and policymakers) from 20 countries through online video-conference. There were four main themes that signified viewpoints and fundamental features of LP to be encompassed in a core outcome measure for LP in PD:

1. Reconfigure expectations of daily living.
2. Ensure wide-ranging applicability and interpretability.
3. Capture changes between modalities and how they impact upon LP.
4. Increase possibility of implementation.

Participants took on board the importance of widely implementing the chosen SONG-LP tool in trials of PD when available. Thus, there is a necessity for it to be concise, flexible delivery in various formats such as paper, phone app etc. and translatable into additional languages (Cheetham et al. 2022).

PD can assume an increased burden of self-care in PD persons' homes and day-to-day life, which could cause stressors for them and their partner, families, and caregivers. Participants receiving APD in a qualitative study in Australia used cognitive, emotional, and behavioural strategies along with a reliance on social supports to adapt to their therapy. The findings have contributed to proposals for dialysis care to enhance emotional well-being and coping that could be included into a forthcoming theory of comprehending adjustment to and coping with KD. These include routinely obtaining and reassessing patient preferences, personalising patient education and peer support, routinely evaluating and appraising psychosocial needs,

and supporting patient emotional well-being. Both the psychosocial pros and cons of APD should be particularly contemplated in pre-dialysis education and should assist in shared decision-making (Duncanson et al. 2021).

The sometimes-shrouded nature of home therapies has diverse significances for patients. Both disease milestones and times of transition can heighten emotional challenges wherein professional psychological support may be embraced by some individuals. Further investigations could include reviewing interventions that both assess and educate coping skills along with the caregivers' perspective (Duncanson et al. 2021).

Fissell et al. (2021) in a US single centre study outlined the novel concept of mindset for comprehending cognition, psychology, and decision-making in adults receiving PD. A health mindset is a person's belief about capabilities to change to enhance health. There is a necessity to support strategies to enhance prevalence and perseverance of home therapies as people may commence PD but following complications can transition to HD. The Health Mindset scale was used ($n = 101$) to depict the range of fixed versus growth mindset as applicable to health. Both HL and health self-efficacy were also measured. Health self-efficacy was strongly related to growth mindset. Individuals may be identified through use of the health mindset scale who may gain from directed interventions to enhance mindset and promote PD modality specific perseverance (Fissell et al. 2021).

The importance of PA and physical function in life participation is a crucial PRO for individuals receiving PD. The Global Renal Exercise Network and ISPD reviewed evidence and international clinical experience to develop a set of clinical practice points for persons receiving PD. There was a sparsity of quality evidence to support clinical practice in this area; thus, expert consensus was reached by persons receiving PD, experienced PD exercise investigators, along with expert clinicians in PD exercise. There were various clinical practice points addressed, such as the timing of exercise and activity (such as empty or full peritoneal space), the interest of particular activities (such as work, sex, swimming), possible unfavourable outcomes associated with activity and exercise (e.g. exit site care, fatigue, sweating, cardiovascular concession, intra-abdominal pressure), and the impact of exercise and activity on areas of interest (such as mental health, reduced fitness, obesity and frailty) and exercise nutrition (Bennett et al. 2022).

The use of assisted home dialysis, including that of assisted PD (asPD), refers to the provision of assistance to individuals with PD by family members and/ or caregivers and/ or professionally trained dialysis nurses,

community healthcare workers, personal support workers, or other skilled assistants (Perl et al. 2023). The accessibility of asPD increases access to dialysis at home, specifically for the growing numbers of older and frail people with advanced KD (Brown et al. 2022). This assistance can vary and depends on the individual's requirements and can be partial or complete, temporary, or permanent, and paid or unpaid. It can be non-technical, such as bringing dialysate bags into the individuals' room. Technical assistance can entail setting up the PD dialysis machine and dialysis-related processes. Clinical assistance includes assessment of the individual's exit site and fluid volume (Perl et al. 2023).

In some European countries, asPD has been used extensively for many years; however, it remains inaccessible or poorly employed in others. Brown et al. (2022) established a group of European nephrologists consequently to the necessity to increase access to asPD across Europe as a way of facilitating individuals with advanced KD who were incapable to conduct dialysis themselves to still have their dialysis in their own home. Following completing a proforma concerning asPD it was established by this group that only 5 out of 13 countries surveyed offered publicly funded reimbursement for asPD. The availability of asPD should be prevalent in every renal centre and country in Europe. The main priorities to enable this process are education, including education of HSPs about the benefits of PD and conversations with individuals and their families as they approach the necessity for dialysis. There also needs to be engagement with both policymakers and healthcare providers to both develop and advocate assistance for PD (Brown et al. 2022).

The necessity for kidney supportive care in PD patients may be even bigger than those that are receiving HD. This is because of a number of issues. There is possibly more complexity and bigger decision-making with a diverse range of therapies to consider, the bigger extent of prognostic indecision with less obtainable prognostic tools, potential variances in type or range of symptoms faced, and subsequent relevance of comprehending personal PD patient motivations. These concerns require consideration to ambitious, longitudinal, goal-focused dialogues that modify individuals' values and significances throughout time. Individuals receiving PD and healthcare providers will be better prepared to make dialysis choices through the window of personal goals and priorities by means of a kidney supportive care person-centred approach to KD care. They can also constantly reframe their kidney treatment decisions in the wider context of an enduring and possibly changing disease trajectory (Lu and Chai 2021).

KIDNEY TRANSPLANTATION

KT is viewed as the best treatment option for patients with KF requiring KRT (Lai et al. 2020). However, KT is a momentous experience that encompasses intense emotional, relational, and social transformations both for the individual and their family situation (De Pasquale et al. 2020). The preparation for KRT or CM should commence 1 year prior to therapy required, including those individuals who have a failing transplant (NICE 2018). Whilst Kharbanda et al. (2020) suggest a timeframe of 6 months for listing possible recipients for KT prior to expected commencement of KRT. The process should be completely individualised. The individual and their family members and caregivers (as applicable) should be included in shared decision-making throughout this assessment process. This incorporates clinical provision, psychosocial appraisal, planning and support, the individuals wish for type of KRT and when to commence and how choices are possibly to influence daily life. There should be additional assessment by a clinical psychologist or psychiatry for every child and young person being contemplated for a KT (NICE 2018; Kharbanda et al. 2020).

Adults who may have adverse outcomes identified should also be regarded for additional assessment for example a deficit in social support, neurocognitive condition, non-concordance (such as medications, dietary, healthcare appointments), limited comprehension of procedure and intricacies of treatment, inadequately managed mental health conditions, or SMI and substance abuse or dependency (NICE 2018; Kharbanda et al. 2020). McCulloch and O'Leary's (2022) narrative review identified that there is limited evidence to propose psychosis as a contraindication to transplantation regardless of it often being seen as such by transplant teams. Positive outcomes instead are reliant on other aspects, including stability of symptoms, motivation, and social support.

It is important to recognise, though, that transplantation on its own can be an extremely stressful occurrence, which could activate trauma memories. The need for enhanced psychosocial assessment and support should be acknowledged instead of viewing this as merely a contradiction for treatment. Additional research should explore building resilience of individuals who have considerable mental distress. For example, some individuals' experiences will empower them to acquire coping strategies that could also assist them to cope with the burdens of a transplant (McCulloch and O'Leary 2022).

There is a necessity to discuss individual aspects of a transplant that influence the risks and advantages of KT

with all individuals who are expected to require KRT and their families and caregivers. Living donor transplantation should be included in this discussion concerning choices for KRT. A pre-emptive living donor transplant should be provided where there is an appropriate living donor. This is regarded as the ideal initial choice for KRT in suitable individuals. Following a complete assessment and if the individual is deemed eligible, they can be placed on the preemptive listing for deceased donor transplantation. A BMI alone should not exclude individuals from obtaining a KT (NICE 2018; Kharbanda et al. 2020). It must be remembered that transplantation does not occur in clinical isolation, as the majority of pretransplant patients have been exposed to CKD and all its associated complications. This must be taken on board when assessing the individual for transplantation and their overall health along with the possible long-term impact of previous and current KD, which could necessitate decades of clinical follow-up post-successful KT (Danovitch 2010a, 2017).

KT imparts significant survival and QoL advantages for many individuals with ESKD compared with dialysis (Ju et al. 2019). The SONG-Tx global initiative has established six core outcomes that should be reported in all KT trials (Howell et al. 2016; Sautenet et al. 2018; Tong et al. 2018). In conjunction with clinical outcomes relating to allograft loss, CVD and mortality, cancer, and infection, LP was the PRO of greatest relevance to recipients, caregivers, and HCPs (Ju et al. 2019; Tong et al. 2022). However, participation in daily life activities can be impaired by complications and side effects of immunosuppression. LP is a significantly relevant PRO for KT recipients (KTRs) but is uncommonly and inconsistently measured in trials (Ju et al. 2019).

The SONG-Tx LP consensus workshop was held ($n = 16$ KTRs and $n = 9$ caregivers and $n = 33$ HCPs from 8 countries) to establish an outcome measure for LP for usage in each trial in KT. The transcripts from the six facilitated breakout groups were analysed, with four themes identified:

1. *Returning to normality* expressed the individuals' goals to accomplish their roles (i.e. family, work, and community) and rebuild a normal lifestyle post-transplant.
2. *Recognizing the diverse meaning and activities of 'life'* clearly recognised LP as a personal concept that could refer to diverse activities (e.g. occupation, leisure, and family responsibilities) for each individual patient.
3. *Capturing vulnerability and fluctuations post-transplant* (e.g. owing to side effects and

complications) addressed the differentiation between the experiences during the first-year post-transplant along with the long-term influence of transplantation.

4. *Having a scientifically rigorous, feasible, and meaningful measure* was estimated to facilitate reliable and recurrent assessment of LP in trials in KT.

These first and second themes relate to the content to be depicted in the measure, whilst the third and final themes are associated with measurement characteristics. There is a necessity for an achievable and substantiated core outcome measure for LP so that this significantly relevant PRO can be reliably and meaningfully assessed in trials in KT to advise decision-making and care of KTRs (Ju et al. 2019).

Burns et al. (2017) explored the lived experiences of individuals waiting for a kidney transplant from a deceased donor whilst receiving KRT in Australia. This study highlighted that those individuals waiting for a transplant are overpoweringly hindered by their exposure to KRT. The concept of receiving a kidney transplant provides them with 'hope that one day they will be free'. However, uncertainty continues when they are concerned as to the length of time waiting for a KT as well as whether the transplant really affords them with the freedom they covet. Social networks, including family members and fellow individuals on dialysis, were identified as beneficial to those who waited. There were multifaceted emotions felt towards the deceased donor with aspirations that an organ would be available quickly; whilst valuing the immense cost to the donor and their family: 'Wishing for a transplant is like wishing for someone to die'.

LIVING KIDNEY DONORS

A living donor kidney transplant (LDKT) would nearly always be the preferred choice, with greater transplant and patient survival than for deceased donation (Andrews and Burnapp 2018, on behalf of the British Transplantation/Renal Association guidelines for living donor transplantation). However, living donation contests the ethical principle of non-maleficence in that it exposes healthy individuals to risks for the benefit of another individual. This generates safety, informed consent (IC), and education a priority. There are numerous benefits for the potential donor with living kidney donation but there are also associated short- and long-term risks. Whilst complete standardisation of IC is possibly unachievable, studies have highlighted the necessity for a standardised IC process to facilitate equitable educational and decision-making expectations for the deterrence of inequalities among transplant centers (Grossi et al. 2023).

The DESCaRTES (Developing Education Science and Care for Renal Transplantation in European States) Working Group of the European Renal Association recommend a three-step model (Grossi et al. 2023). This is established on the shared decision-making Three-Talk Model by Elwyn et al. (2017). Each step concurs with the three ideal timings of the process guiding the living donor (LD) to the verdict to participate with living donation:

1. Prior to the necessity for KRT, there is a team talk.
2. There is an option talk with transplant HCPs at the local nephrology unit or transplant center before evaluations commence.
3. During evaluation, specifically if there are second thoughts or uncertainties following learning about the various facets of donation, there is the decision talk (Grossi et al. 2023).

The DESCaRTES recommend standardisation of the timing, content, modalities for imparting risks and assessment of comprehension preceding to donation. The Three-Talk Model permits a successful combination between standardisation and individualisation of IC, facilitating a person-centred approach to possible donors (Grossi et al. 2023).

The Human Tissue Authority (HTA) in the UK advocates that all living donation regulations for organ transplantation must be sanctioned by them prior to any donation occurring. This includes that no remuneration has been or will be provided; and consent has been provided for removal for the intent of transplantation. Living donation can only be warranted if the interests of the donor are given prevalence irrespective of recipient benefit. Both safety and welfare of the potential LD must take priority always over the possible transplant recipient (Andrews and Burnapp 2018). There must be ongoing continual support for the potential donor, recipient, and family members, which is an essential component of the donation/ transplantation practice. There must be an identification at an initial stage of the emotional needs to enable that suitable support and/ or intervention is introduced that could be referral to specialist psychiatric and psychological services (Andrews and Burnapp 2018; Chadban et al. 2020). There can be distress for both the donor and recipient if the potential donor is not able to donate because of a clinical rationale. This can ensue anguish for both parties and may relate to negative emotions of failure, fury, or blame. This could subsequently result in depression or other negative emotional outcomes. There is a necessity with this situation to anticipate and sufficiently provide emotional support. It can also be stressful for both donor and recipient and

relevant family and friends whether to continue with living kidney donation and to make this decision. This decision-making process as to which donor should continue if there are a few family members considering donation can be complicated. The healthcare team play a crucial role here with providing relevant cohesive information at an initial stage so that relevant parties are as fully informed as feasible and make a choice (Andrews and Burnapp 2018; Chadban et al. 2020).

Lentine et al. (2017) on behalf of the Kidney Disease: Improving Global Outcomes (KDIGO) clinical practice guideline on the evaluation and care of living kidney donors identified that psychosocial evaluation assists in determining if a donor candidate is psychologically fit for donation. There is a need for education and planning sessions with experienced HCPs to discuss the psychosocial evaluation and the process involved with the donor candidate. These sessions will advise the donor candidate that they should have a good QoL following donation; however, they should be advised that some individuals may experience psychosocial difficulties following donation. These sessions should concentrate on any worries that the donor candidate may have and ensure that any possible psychosocial risks and benefits of kidney donation are revealed and understood. The psychosocial evaluation can also be used to devise a plan to assist the donor candidate in having a positive psychosocial experience during the evaluation and donation procedures, and long-term following donation. Transplant programmes should adhere to procedures for assessing psychosocial factors that either exclude donation or stop any further evaluation until there is a resolution (Lentine et al. 2017).

There are many challenges in transplant-particular emotional adjustment facing both living donor recipients (LDRs) and deceased donor recipients (DDRs) with evidence recognising emotional adjustment limited. In a study in Singapore, 182 KT patients ($n = 106$ LDRs, $n = 76$ DDRs) completed a depression, anxiety, stress scale, and transplant effects questionnaire. The LDRs were a younger cohort and more educated. Both groups experienced moderate to severe symptoms of anxiety, with younger participants highlighting greater risk of adverse emotional adjustment. There is a necessity for additional interventions aiming at improving anxiety and transplant-specific worry (Lai et al. 2020).

POST-KIDNEY TRANSPLANT

The care after KT should not only encompass immediate post-operative surgical care and management of immunosuppression but also incorporate management of the

failing and failed kidney allograft (Josephson et al. 2023). The monitoring of mental health does not finish when an individual receives a KT. There is major responsibility with a KT that derives its own demanding challenges and difficulties that could cause, or escalate, an individuals' depression (Jones 2020). Depressive symptoms, anxiety, and fatigue can depict as a symptom cluster known as *sickness symptoms*. These are prevalent amid individuals with a long-term condition. Sung et al. (2023) scoping review integrated available evidence for sickness symptoms in KTRs. There was no identification from the studies of sickness symptoms as a cluster; however, observations were noted of the interrelations amid the symptoms investigated, with fatigue the most prominent sickness symptom and anxiety and depressive symptoms following. Prognostics of these symptoms encompassed demographic, clinical, and psychosocial features and HRQoL was the highest researched outcomes (Sung et al. 2023).

Support for the recipient of a transplant can be divided into two major components: the psychosocial evaluation for transplant candidacy and symptom management post-transplantation. There is a bidirectional association between mental illness and KD. Poor transplant outcomes are related to co-occurring psychiatric conditions. This has been ascribed to behavioural influences such as non-concordance (non-adherence) along with physiologic factors, for example alteration of immunologic and stress reactions. There is a need for a biopsychosocial evaluation of individuals' post-transplant, addressing issues such as mood or worries, changes in perceptions, morose thoughts concerning self-harm or harm to other persons, behavioural symptoms including concordance, taking risks, and substance abuse, along with environmental and personal stressors. These areas may be tempered by positive influences including social support, perception, spirituality, and the usage of adaptive coping methods (Danovitch 2010b; Shenoy and Danovitch 2017).

There are two main goals in the first-stage management of KT – avoiding acute rejection and avoiding opportunistic infection. The purpose of the second or later stage is to retain good graft function along with deterring the long-term consequences of immunosuppression such as infection, malignancy, and premature CVD (Baker et al. 2017; Pham and Danovitch 2017). The foundation for the care of KTRs is that of education, as individuals need to acquire self-care skills including spotting the signs and symptoms of rejection (Murphy 2014, 2019). It is important that there is a continuous MDT alliance when discharging individuals from the transplant unit home and into the primary care setting (Murphy 2011).

Individuals may encounter numerous psychosocial risks post-transplant, which may have a negative impact on all concerned. Their family dynamics and working background may be changing, with some individuals finding it challenging to move away from the dependent 'sick role' that they experienced on dialysis. The new associated freedom that comes with a transplant could be a risk to those persons who identified themselves within the sick role, and it can be challenging to make the transition to health. Guilty feelings may be expressed by individuals who have received a kidney instead of another person. However, there is a need to re-emphasise that these emotions are common and that they are worthwhile in terms of receiving this altruistic donation from the donor and their family (Hersh-Rifkin 2010, 2017). Jones (2020), however, suggests that there needs to be an acknowledgement of the stigma that has developed within the KD community that if an individual receives a KT, then they do not have the right to disclose any of negative attributes or it will appear that they are complaining and are unappreciative. This stigma could preclude recipients from pursuing necessary treatment for their mental health (Jones 2020). The social aspects of dialysis sessions may also be missed by some individuals. These issues and concerns may result in personal relationship difficulties with partners and family members, along with anxieties about entering the workplace or genuine concerns about losing financial assistance such as potential disability benefits (Hersh-Rifkin 2010, 2017).

The aim of a qualitative phenomenology study by McKeaveney et al. (2022) was to develop an in-depth comprehension of the lived experiences of KTRs ($n = 23$) within two regional nephrology units in the UK. Participants regarded graft failure as life-threatening, resulting in fluctuating levels of anxiety of dialysis starting, re-dialysis, re-transplantation, or equally instant death. These ongoing fears and distress became amplified with the new vulnerability to the COVID-19 infection. There were reflections made by participants concerning the psychosocial challenges pre- and post-transplantation. These involved challenges surrounding treatment decision-making, evading talks regarding living donation, diminishing work, reconsidering relationships, and disillusionment to recognise impending life goals adding to previously isolating reality. The participants' journey was a dominant theme throughout the findings and outlines that their experiences highlighted that there needs to be an understanding of the entire timeframe living with of a KT (i.e. pre-, and post-transplant); leading to enhanced integration into emotional support and information in renal healthcare (McKeaveney et al. 2022).

De Pasquale et al. (2020) systematic review highlighted that pre- and post-transplant screening process should comprise a medical evaluation and an in-depth psychological and psychiatric assessment for enhanced therapeutic adherence. It is vital to prevent and identify non-adherence in KTRs (Baker et al. 2017). The side effects mentioned above could cause individuals to not take their medications as prescribed, so it is important to assess their opinions towards these side effects. Some of the side-effects can be reduced by concentrating on lifestyle, including diet and exercise. Patients can be encouraged to self-manage their care instead of expecting failure. The issue of concordance or adherence can be a major concern due to its highly associated threat for both acute rejection and graft loss. It is recommended to identify factors (see Table 4.2) that are associated with non-concordance and identify the necessity for a care pathway that would assist those persons who are regarded as an increased risk or with recognised non-concordance. Education, prevention, and treatment strategies can be provided to minimise non-adherence. Individual counselling sessions may be necessary to assist individuals and their partners and families in dealing with the life-changing event that transplantation presents. Patient support groups can also assist (Hersh-Rifkin 2010, 2017; KDIGO 2017; Low et al. 2015; Baker et al. 2017).

Cossart et al. (2022) conducted a qualitative study using semi-structured interviews to investigate medication-taking behaviours of KTRs ($n = 14$; transplanted at 60 years of age or older) in Australia. It

considered how KTRs presently manage their immuno-suppressant regimen and how they manage post-transplantation with the intricate routine. The main themes that emerged were variability in HL toward medicines, the relevance of support networks, the necessity to modify health expectations, issues that were motivators for self-care, various approaches to medication management and to medication taking. It was found in general that older adults prioritised medication taking above everything else, and appreciation to their donor was a significant influence to adhere. However, approaches to support medication taking were occasionally ineffective when individuals' routine altered. Future interventions should consider approaches to promote flexible medication taking behaviours that can endure changes in everyday routine (Cossart et al. 2022).

KT can enhance mental health in the widest sense and this on its own is a commanding motivation to endure transplantation in numerous patients. A collaborative mental healthcare approach is crucial to assist individuals adjust to their new post-transplant realism and assist to sustain adherence. Individuals with a KT incline to have lesser rates of cognitive disturbance, anxiety, and depression than individuals receiving HD and PD. Transplant recipients function better on handling speed, attention, short-term memory, and select functioning compared to transplant candidates. However, those that have a transplant endure the continual appearance of graft failure. There will be a need to re-establish their role within the family alongside adapting to enhanced autonomy and return to purpose by many persons living with a transplant. There can be concerns with the challenges of bodily integrity and physical adaptation to the immunosuppressive medications and their associated side effects. Depression can steer towards poor adherence, whilst remission from depression and positive adjustment to KT has been demonstrated to enhance post-transplant outcomes (Shenoy and Danovitch 2017).

Table 4.2 Risk factors for non-concordance of medication (KDIGO 2017).

- History of non-concordance behaviour preceding transplantation.
- Mental health illness.
- Personality conditions.
- Reduced social support.
- High risk behaviour such as substance abuse.
- High education level.
- Teenager.
- Period since transplantation.
- Limited sufficient after care with transplant specialists.
- Inadequate education prior to transplant.
- Challenging medication regimens.
- Numerous adverse effects from medications.

FAILING KIDNEY TRANSPLANT

The recent updated UK guidelines from the British Transplantation Society on the management of the patient with a failing KT includes a new chapter on psychosocial issues (Griffin et al. 2023). Individuals with a failing transplant may need psychosocial support and or intervention. It has been recommended that every individual with a failing transplant should undergo psychosocial screening by renal clinicians using screening and assessment tools endorsed such as the Patient Health Questionnaire-4 (Kroenke et al. 2009); Distress Thermometer (NCCN 2019); the Work

and Social Adjustment Scale (Mundt et al. 2002) and the Medication Adherence Report Scale 5 (© Professor Rob Horne). It must be recognised that being at this stage of their kidney care is emotionally difficult. The use of tailored information should be provided to assist in relieving the individuals' experience of loss, grief, and depression. Risk factors – for example, self-harm and/ or suicidal thoughts, evasion of health decision-making or risk-taking behaviour – must be identified. Psychosocial screening is recommended to occur at the initial attendance to a 'low clearance/failing transplant support clinic'; yearly following the initial appointment; more regularly if there is apprehension about an individuals' psychosocial well-being and when switching therapy modality (De Pasquale et al. 2020; Chadban et al. 2020; Davison et al. 2019; Davis et al. 2022).

Following the screening results, there are three probable outcomes: (1) there is no additional psychosocial support or intervention needed at present; (2) the individual is referred to community support-adult social care or low-level psychological intervention; and (3) the individual has a suitable psychosocial support and intervention plan developed with them, including a qualified psychosocial co-worker in the renal department or continuing referral to mental health services/ psychiatry (Griffin et al. 2023). An adapted four-tier care model of professional psychological assessment, support, and intervention is recommended. This model considers both the variety and diversity of psychosocial skills provided by different professional disciplines. In level, 1 all health and social care professionals will provide general emotional care through listening skills, empathy, and understanding. Whilst health and social care professionals providing level 2 support are necessitated to have had some training in psychological assessment and intervention and receive consistent supervision by level 3 and 4 practitioners. Those practitioners only with a mental health or psychological qualification can deliver level 3 and 4 interventions (Griffin et al. 2023).

KDIGO conducted a controversies conference to focus on when the KT is failing or has failed. It was identified that early communication and psychological preparation and support are crucial factors in patient emotional well-being and adjustment to graft failure (Josephson et al. 2023). It is important to prepare the individual with early discussions even prior to the kidney failing, which enhances planning and individual acceptance. These conversations regarding dialysis modality and type of vascular access should commence as a minimum 6 months before the estimated onset of dialysis as established for example by the estimated glomerular filtration (eGFR) trajectory particularly in those adults without operational vascular

access. The re-transplantation evaluation procedure should commence at a minimum 12 months prior to predicted return to dialysis. Patients should be relisted as soon as they meet eligibility norms in those countries where pre-emptive listing for a deceased-donor transplantation is permissible. Commencing the re-transplantation evaluation procedure early enhances the prospect of detecting a living kidney donor and pre-emptive re-transplantation. Individuals should be completely advised from their initial communication with the transplant team of all potential transplant outcomes, including the potential of the necessity for future re-transplantation. The potential for allograft loss although a challenging area to address should be considered with the individual at the juncture of each immunologic or non-immunologic episode that has the possibility to adversely influence kidney function. Once biopsies are conducted because of reduced kidney function, the trajectory of possible additional decline should be shared, incorporating some broad idea of the timeline for graft survival (Josephson et al. 2023).

The individual must be placed at the centre of the care, promoting patient activation and providing emotional support throughout this challenging time. The importance of communication with the receiving dialysis unit and establishing that the individual comprehends the plan are significant as they transition back to dialysis. HCPs should educate themselves about how CM/ supportive care decisions can assist individuals through periods of transition of care. There is a necessity for more research in this area, including psychological management for individuals with failing and failed allografts (Josephson et al. 2023).

CONSERVATIVE KIDNEY MANAGEMENT (NON-DIALYTIC OPTIONS)

It is important that persons with advanced CKD have all treatment options discussed with them and their partners, families, and caregivers. Many older people presenting for dialysis are frail, require assistance, and have co-morbidities such as heart disease and diabetes. With some older patients, dialysis may be a difficult treatment option and may not necessarily lead to an improved QoL along with prolonged survival (Murphy 2014, 2019).

Winterbottom et al. (2020) undertook a review to appraise patient decision aids (PtDAs) developed to support patient-professional shared decision-making between dialysis and CM treatment pathways. PtDAs are devised to proactively support individuals' reasoning when choosing between therapy options. The findings propose that CM and dialysis decision aid be based on

evidence concerning how individuals with deteriorating KD make decisions concerning their health now and in the future. PTDAAs should also highlight how HCPs navigate the various service pathways to provide care to individuals as their kidney fails and their care needs change (Winterbottom et al. 2020).

Choosing a treatment option is a very personal decision. HD or HHD might be desirable whereas for some individuals might prefer PD. Other individuals who present with serious medical problems might be better advised to manage their symptoms. CM is where the individual opts not to have dialysis but will have continual assistance from the MDT in terms of symptom management and control, emotional support along with palliative care, and social work support (see Chapter 10 on CM for further information).

DEPRESSION

Depression excessively impacts individuals with KD, including those managed without dialysis, KF needing dialysis, and KT recipients (Gregg et al. 2021). Depression can be experienced in 2 to 10% of the general population. However, it is prevalent in 20 to 30% of patients receiving dialysis (Palmer et al. 2013; Ossareh et al. 2014; Treadwell 2017). Individuals living with dialysis have selected depression as a significantly crucial clinical outcome in nephrology trials (Natale et al. 2019). Jennifer Jones from the US lived with KD and has since received a KT; she detailed her experiences of living with depression throughout her journey with KD. 'Depression should be treated as a side effect that is constantly monitored throughout every stage of CKD. This approach could erase stigmas and could change the outcome of so many kidney patients who are suffering from the physical and mental effects daily' (Jones 2020: 1693).

Pearce et al. (2023) conducted a scoping review using a narrative synthesis with the aim to examine the approach for how depression is identified, managed, and treated in adults with CKD. Depression was most recognised using self-report screening tools (85.3%) with variations of the BDI (33.7%) being the most utilised. In terms of managing depression the use of non-pharmacological interventions was more commonly examined ($n = 55$ out of a total of 123 studies). The use of CBT ($n = 15$) was the most frequent non-pharmacological intervention and understood to have a considerable impact on depressive symptoms. However, it was not evident how such methods could be applied as part of routine care delivery. There was inadequate evidence with a limited number of studies for the use of antidepressants

in individuals with CKD. There is a need for more robust RCTs concerning antidepressants, including studies addressing the withdrawal of these medications as well as non-pharmacological interventions (comprising combined methods). There is the necessity for further research to demonstrate more current measures in depression screening tools such as the PHQ-9 and to comprehend how it operates across modalities. Screening procedures need to be progressed to increase recognition of depression at crucial points of kidney care. Additionally, it is essential to have methods and tools that are culturally modified, valid and suitable. There is limited evidence exploring current clinical practice patterns, which is necessary to better comprehend how screening and interventional practices are implemented in routine kidney care. This comprehension of national clinical practice patterns may also enable the advancement of specific kidney guidelines for the detection and management of depression in CKD (Pearce et al. 2023).

Gregg et al. (2021) asserts that every 6–12 months individuals across the range of KD must be screened for depression using self-report questionnaires. An interview with a suitably qualified practitioner should follow to reinforce the incidence of sadness or anhedonia when depressive symptoms are recognised. Gregg and Hedayati (2020) maintain that it is usually more practical for nephrology providers in the clinical setting to identify individuals with depressive symptoms initially by administration of self-report questionnaires. This is to recognise risk if they meet the proven cut-offs followed by verification of the following: (1) the existence of sadness or anhedonia; (2) the existence of symptoms as a minimum for 2 weeks for major depressive disorder diagnosis; and (3) the lack of active suicidal ideation, which could require critical attention or vigilant followup (Gregg and Hedayati 2020).

Kondo et al. (2020) conducted a systematic review to detect depression screening tools (and/or thresholds) suitable for individuals with KF and to better comprehend the impact of screening for depression in this population. The BDI Inventory II was the best studied along with an extensive range of thresholds described. Shorter assessment tools such as the PHQ-9 and the Geriatric Depression Scale 15 (adults > 60 years) executed well but were not well studied. The use of the BDI-Fast Screen may be a suitable option for a preliminary screen. The findings also identify that there is inadequate research evaluating the diagnostic precision of most screening tools for depression in individuals with KF with shortcomings in both methodology quality and/ or reporting. The authors suggest that the current studies may not be generalisable to US populations. HCPs should be willing to approve positive screens

prior to making treatment decision that could be burdensome or initiate the likelihood of harm. There is a necessity for further research aimed at extensively used, free tools such as the PHQ-2 and the PHQ-9 (Kondo et al. 2020).

Lin et al. (2020) cohort study ($n = 275$) in China identified that the frequency of depressive symptoms in individuals receiving CAPD was 31.3% with female gender, diabetes, and reduced eGFR all independently correlated with depressive symptoms in this group. An increased risk of all-cause mortality and technique failure were independently associated with depressive symptoms. There is a necessity for closer monitoring of individuals' psychological difficulties when they attend the PD clinic, including frequent screening to detect depressive symptoms along with suitable intercession and treatment, which may enhance clinical outcomes for these adults. Sleep disturbance and depression are highly predominant symptoms in individuals receiving HD and are associated with adverse clinical outcomes. A correlational cross-sectional study in Saudi Arabia (Almutary 2022) investigated the influences of depression and excessive daytime sleepiness (EDS) on QoL of adults undergoing HD ($n = 180$). The results demonstrated that more than 50% of adults on HD had depression (a main predictor of lower QoL scores) and about 33% had EDS (Almutary 2022). These studies aligned with findings in other studies (Al Naamani et al. 2021; Al-Ali et al. 2021; Palmer et al. 2013).

Dziubek et al. (2021) assessed the frequency of depression symptoms and anxiety and measured the level of life satisfaction within three cohorts of adults in Poland living with KD ($n = 283$) based on stages 3 and 4 CKD ($n = 94$), stage 5 CKD on HD ($n = 87$), and post KT ($n = 102$). The BDI, the Satisfaction with Life Scale (SWLS), and the State-Trait Anxiety Inventory (STAI) were used. Anxiety as a trait was identified to be the factor most substantially allied with depressive symptoms within the three cohorts of adults. Those adults in the dialysis cohort had the highest percentage of depressive symptoms; whilst those in the pre-dialysis group (stages 3–4) had the lowest percentage with high satisfaction with life. There was a significant association between BDI and SWLS and STAI in all cohorts whilst a significant association was noticed amid BDI and handgrip strength in those individuals on HD and KT. It is necessary no matter what stages of CKD (including that of KT) that the emotional status of individuals is both screened and monitored (Dziubek et al. 2021).

Bossola et al. (2017: 414) maintain that individuals 'care little for PTH, Kt/V and phosphate values but much about comfort, mobility, functionality, energy level, sleep and mood'. This absence of consideration by healthcare

providers to what individuals regard as their quality objectives is challenging. Treadwell (2017) suggests that Orem's theory of self-care deficit is suitable for recognizing depression, discerning motivation for change, and inspiring self-care practices. Utilising the theoretical framework of Orem's nursing process, the capacity to highlight and address psychosocial concerns in adults may offer essential information to support them with self-management skills to enhance concordance and QoL. There is a need for large clinical trials to ascertain the best method to manage depression in individuals with ESKD (Treadwell 2017; Pearce et al. 2023).

Gerogianni et al. (2019) outline a variety of treatment methods for anxiety and depression in people receiving HD that may be diminished by a diversity of therapy approaches including CBT, pharmacological, routine exercise, relaxation techniques, and acupuncture. Intradialytic exercise training schedules also has a positive influence on individuals' physical and emotional functioning. The importance of social support from family and friends alongside social background and the delivery of education and information typically leads to a decrease of anxiety and depressive symptoms. There is a necessity for a comprehensive psychiatric evaluation of individuals receiving HD for initial detection and treatment of depressive symptoms (Gerogianni et al. 2019). Gregg et al. (2021) highlights the use of therapy through pharmacological measures such as selective serotonin reuptake inhibitors, which has not constantly demonstrated benefit compared with placebo and may be related with serious adverse outcomes including cardiovascular events. A watchful trial with careful observation based on the accessibility of alternative therapies for therapeutic and adverse effects is acceptable, including the use of CBT and physical exercise. These should be recommended to individuals who have access and are agreeable.

Natale et al. (2019) updated their Cochrane review to evaluate the impact of using psychosocial interventions against standard care or a second psychosocial intervention for averting and managing depression in adults with ESKD receiving HD. The use of CBT, exercise, or relaxation techniques possibly reduced depressive symptoms (with evidence of moderate certainty). The HRQoL was possibly enhanced using CBT. The use of counselling could slightly reduce depression amid those receiving HD. There was a low certainty of evidence for the use of spiritual practices, acupuncture, telephone support, and meditation. There was also low or very low certainty of evidence for impacts of psychosocial interventions on suicide risk, major depression, hospitalisation, withdrawal from HD, and adversative outcomes (Natale et al. 2019).

SEXUALITY

Sexual dysfunction has been associated with reduced HRQoL, anxiety, and depression (Johansen 2020). It is common in individuals living with CKD and has been identified as an important research gap (Harrison et al. 2020). There is a high prevalence of sexual difficulties in patients with CKD, with 75% of men receiving dialysis experiencing erectile dysfunction and 30–80% of women with symptoms associated with sexual dysfunction (Navaneethan et al. 2010). This systematic review and meta-analysis of observational studies highlighted that, despite the incidence and clinical importance of this area, there were many limitations to the studies reviewed, including a poor response rate and lack of validated tools to assess sexual difficulties. There were also limited studies addressing this area in women with non-dialysis CKD (Navaneethan et al. 2010).

Pyrgidis et al. (2021) identified that in women with ESKD, sexual dysfunction (SD) remains underestimated. They subsequently conducted a systematic review and meta-analysis to investigate the prevalence, correlates, diagnostic approach, and therapy modalities of sexual symptoms in women with ESKD. The pooled Female Sexual Function Index (FSFI) scores were determined. There were 47 studies included with 61 patient group entries and 3490 women with ESKD. The SD incidence in all women with ESKD was 74%. The SD in those women with HD was 80%, 67% in PD and 63% in women with a KT. Both older age and menopause were related with higher incidence of SD. The total FSFI score augmented post-KT. Female SD is extremely prevalent in women with ESKD, but KTRs described better sexual function. QoL is negatively impacted by sexual symptoms and necessitates suitable clinical interventions. There is a necessity for studies on methods of treatment of SD in women with ESKD, as these are limited along with the need for clinical recommendations in this area (Pyrgidis et al. 2021).

A literature review was carried out by Chou et al. (2021) to describe the pathophysiological and the psychosocial causes of SD regarding KRT – specifically HD and PD. This review highlighted that there is substantial heterogeneity when comparing SD between different KRT. There are no clear guidelines for transferring modalities for individuals for example to resume menstruation, improve libido, and standardise hormonal profiles. The intricate and multifactorial causes of SD is a major impediment, and comorbidities that also impact individuals can add to these difficulties. Whilst KT enhances many facets of sexual function and fertility, it is far from without its challenges. Iatrogenic causes of SD can also be a source of

exasperation for individuals with KD and HSPs alike. Additionally, the delicacy and stigma associated with SD has been an established barrier to advances in clinical practice. There exist many disparities for both men and women in this area of research. There is a necessity for robust RCTs and large cohort studies to address the numerous unknowns in the detection and management of SD in individuals with KD. Sexual function as a recognised predictor of QoL should become an aspect of focus in the quest for patient-centred care specifically to enable individuals living with dialysis to achieve as ‘normal’ a life as feasible (Chou et al. 2021).

The development and expression of sexuality is influenced by biological and psychosocial factors. Sexuality can be a challenging concept to define. It is a multidimensional concept that incorporates a wide range of enjoyable sexual activities that may or may not include coitus but also touching, kissing, and embracing. It also includes body image, self-esteem, self-image, and how other individuals perceive each other. It can be viewed that being a sexual individual is healthy. Therefore, participating in sexual intimacy might permit a means of helping individuals who are living with long-term condition to feel ‘normal’ (Sheils 2003; Lemieux 2004; Murphy 2012; National Kidney Foundation 2023).

Many contributory factors can lead to the development of sexual difficulties whilst living with KD. These include medications, alterations in hormones, vascular, neurological, and psychological factors (Navaneethan et al. 2010; Johansen 2020, Chou et al. 2021). Table 4.3 indicates the numerous physical and psychosocial sexual concerns associated with living with CKD. These sexual concerns do not just affect individuals themselves but also their partners. It can affect their overall QoL and can impact significantly on their personal and overall family relationships. It can also be challenging for individuals who are not in a relationship and who may be looking to meet a partner, or for those that are content not being in a couple, as overall body image can be altered when living with KD (Murphy 2014, 2019).

Body image is intertwined closely with sexuality. Individuals living with PD and HD require vascular access surgery, which can lead to scars and potential deformities. There is also the psychological impact on how people feel with a potential foreign body in terms of a PD catheter inserted into their abdomen or living with a central venous catheter (CVC) in the neck or an AVF in their non-dominant arm. They may feel that such vascular access is a constant reminder of living with their long-term illness. This may be regarded as the individual’s ‘lifeline’ and therefore must be monitored carefully. Concurrently individuals can feel unattractive and self-conscious of these lifelines

Table 4.3 Physical and psychosocial sexual concerns living with CKD. Adapted from Auer (2008) and Levy et al. (2016).

Men	Women	Men and Women
Tiredness	Tiredness	Anxiety, stress, and depression
Decreased libido	Decreased libido	Fear of failure
Sexual arousal difficulties	Sexual arousal difficulties	Struggle in relationship with partner
Erectile dysfunction	Absence of vaginal lubrication	
Premature or delayed ejaculation	Pain during intercourse; Difficulty in achieving orgasm	Roles changes leading to reliance
Difficulty in achieving orgasm	Altered menstrual patterns; Anovulation	Sense of guilt towards partner
	Fertility problems	Diminished confidence in sexual identity
		Changes in body image and reduced self-esteem

and may alter their self-image accordingly, such as avoiding wearing short-sleeve tops or keeping their shirts or tops buttoned up to avoid showing their central lines or fistulae when out in public, in case they attract people staring (Murphy 2014, 2019). Silva et al. (2018) used a qualitative exploratory study ($n = 30$) in Brazil to comprehend the experiences of individuals receiving HD using AVFs. The study highlighted that vascular access results in signs that alter the body aesthetics leaving it damaged. These changes result in low self-esteem and embarrassment with individuals camouflaging their AVFs. They may also find it difficult to undress in front of their spouses and partners or become intimate, for fear of being rejected by them. This may be a more significant issue in individuals living with PD in terms of their abdominal catheter and positioning it when trying to be intimate with their partners (Murphy 2014, 2019).

Individuals who were on HD because of KF was asked to perceive their bodies as considered in drawings and narratives. The participants ($n = 29$) completed an anonymous questionnaire which contained the following instruments: the Centre for Epidemiological Studies—Depression (CES-D), Multidimensional Body-Self Relations Questionnaire (MBSRQ), and the MOS 36-Item SF health survey. Individuals drew their self-figure prior to and after their diagnosis of KF. The findings highlighted elevated levels of depression and concerns regarding body fitness and weight (Lev-Wiesel et al. 2022). Individuals can also complain of abdominal discomfort and distension with dialysate fluid, which can impair their body image regarding clothes size having to be increased to accommodate an extended abdominal girth. This can, again, all impact on their self-esteem and overall body image, leading to them potentially feeling unattractive, unwanted, and depressed and leading to social isolation. One could argue that there is a double-edged sword with regards to the use

of some medications that individuals must take to manage their treatment, such as antihypertensive drugs, and possible side-effects in men for example such as erectile dysfunction (Murphy 2014, 2019).

The use of immunosuppression medications with KTRs can result in side effects that can affect body image such as hirsutism and weight gain. These side effects are usually temporary and can be managed. Body-image concerns may not always be obvious to individuals and their partners. They might not be discussed or addressed by either party or within the transplant unit. There is a need for sensitivity and open discussion by the relevant HCPs (Murphy 2012; Hersh-Rifkin 2010, 2017). Women, for example, may be anxious to conceive post-transplant and may potentially risk their transplant if they do not concord to the recommendations of planning for conception and being carefully monitored by kidney and maternity health-care providers throughout the pregnancy (Murphy 2014, 2019). The UKKA clinical practice guidelines on HD advocate counselling women of reproductive age who are undergoing or intending to start dialysis, so that they are advised of the connections between KRT and pregnancy, which could affect family planning and modality choices. They recommend altering as soon as feasible to an individualised, enhanced HD schedule for women wishing to maintain their pregnancy. This should be as a minimum 20 hours weekly provided over at least six sessions (Ashby et al. 2019).

The UKKA clinical practice guidelines on the post-operative care in the kidney transplant recipient (Baker et al. 2017) and pregnancy and renal disease (Wiles et al. 2019) identified that women should wait for 1 year post transplant and have stable function before attempting conception. The advice concerning contraception should be comparable to the general population. Women and their partners should be offered counselling regarding fertility

and reproduction either before transplantation or soon afterwards. Prior to conception, applicable immunosuppressants as advised should be discontinued and substituted as appropriate. The advantages and disadvantages of breastfeeding should be considered. It is suggested that there should be care pathways for managing SD. This issue should be discussed ideally at the annual review clinic. It is recommended that there should be close cooperation with local andrology facilities. The drug Sildenafil is safe and effective in males post-KT not prescribed nitrates (Baker et al. 2017). The findings from a systematic review and meta-analysis evaluated the effect of KT in individuals in men with ESKD and erectile dysfunction (using the same study population pre- and post-KT) established improvement in erectile dysfunction post KT in comparison to pre-KT evaluation (Miron et al. 2023). Sexuality is not just relevant with patients who are receiving dialysis and KT but also those that have chosen CM. It can remain an integral part of their lives and should not be assumed that it is not relevant towards end-of-life care. The concept of emotional connection may take priority over the physical aspect of sexuality at this stage of the patient's life (Murphy 2012).

The management of these sexual difficulties includes optimising dialysis treatment, addressing dietary, anaemia, endocrine abnormalities, and hyperparathyroidism issues, reviewing drug therapy and erectile dysfunction and psychosocial issues (Levy et al. 2016). It is important to broach this sensitive subject with individuals because if members of the healthcare team, especially nurses, do not do so, there can be a strong possibility that patients will not introduce this subject as they could feel embarrassed and uncomfortable in discussing it. Renal nurses must be comfortable with their own sexuality to discuss this subject and put aside their own preconceived ideas. They must be good communicators and be able to recognise when some individuals do not want to discuss this subject, watching for verbal and non-verbal cues and being mindful of cultural issues and the physical environment at the time in terms of privacy (Murphy, 2012, 2014, 2019).

Not all individuals living with KD identify sexual concerns as being an issue for them; this must also be acknowledged by nurses. However, the matter should be introduced and then it should be ascertained whether this is an issue for further discussion. It is important to involve the individual's partner as much as feasible to enable them to feel included in this process and to ascertain their experiences. Individuals must be educated in how to manage these sexual concerns and where to seek further assistance and advice, as nurses are usually not trained counsellors (Murphy 2012, 2014, 2019). Kidney Care UK and the

National Psychosocial Working Group (2022) identified that an individuals' level of need should direct the required psychosocial interventions. The kidney healthcare team needs to be educated in how to discuss this subject and to recognise that it can be a real and valid concern for individuals with KD. They must acknowledge that this area is an intrinsic part of their care delivery. Should this intrinsic aspect of care not be addressed by nurses who are usually at the front and centre of care delivery; individuals with KD could needlessly suffer in silence (Murphy 2012, 2014, 2019).

CAREGIVERS' ROLE

Caregivers' role must be acknowledged and the impact that this role has on them. They play a crucial role in supporting individuals living with long-term conditions. A caregiver is usually an informal carer who tends to be a family member of the individual patient. They undertake a diverse number of duties including arranging transport to healthcare appointments, dispensing treatments, dietary assistance, and supporting with home therapies. Caregivers of individuals living with KD have expressed feelings of fatigue, anxiety, depression, and burnout. The role of the caregiver has become more noticeable throughout the COVID-19 pandemic with the growth of remote services and telemedicine (Subramanian et al. 2019). Family dynamics can be impacted when an individual living with advanced CKD is relying on the ongoing support of a caregiver. It can contribute to additional burden on the caregiver themselves as the individual becomes more reliable on the caregiver to the potential detriment of the caregivers' own priorities and life goals (Kalantar-Zadeh et al. 2021).

Williams et al. (2017) highlights that male caregivers of persons living with advanced CKD experience burden and symptoms of depression as well as alterations in their physical health because of their care provider role. The findings of this study suggest that the male care providers share similar experiences to female care providers of persons living with advanced KD. Ghahramani et al. (2022) conducted an RCT to examine the efficacy of a designed peer mentoring (PM) programme on burden of care amidst caregivers of individuals with CKD. It is well documented that CKD is associated with an intensified burden on caregivers. The concept of PM enhances numerous outcomes in many long-term conditions. There were three groups of caregivers randomised ($n = 86$) to obtain 6 months of intervention; group 1 ($n = 29$) face to face; group 2 ($n = 29$) online PM; and group 3 ($n = 28$) usual care: textbook only. There was 16 hours of instruction provided to peer mentors; every participant accessed comprehensive information

about KD via a copy of a textbook. Online PM was identified as a valuable strategy that leads to decreased caregiver burden in CKD. COVID-19 pandemic highlighted the necessity for online substitutes to face-to-face mentoring. Online programs also permit access to mentoring by people with reduced ability to travel and for areas with inadequate resources (Ghahramani et al. 2022).

DePasquale et al. (2019) investigated unforeseen negative experiences with ESKD therapies amid family members of dialysis (ICHD and home therapies) and individuals post LD transplantation in the US to recognise significant focus for family-centred research and clinical care. Participants engaged in eight focus groups with 49 family members in total; four themes emerged. These included becoming a caregiver with unexpected responsibilities and sleep disturbances, poor emotional therapy reactions in patients (e.g., depression) and family members (e.g., anxiety), treatment delivery and logistical information, and dialysis-associated health issues and fatigue. It showed a need for more family-centred individualised care though education and interventions to prepare them earlier for ESKD therapies with a need for more collaboration and effective communication with all key partners (DePasquale et al. 2019).

Carswell et al. (2021b) identified that there are limited studies concerning the experiences of informal carers for those individuals who have KF and opted for CM instead of dialysis therapies. These informal carers can experience high degrees of psychosocial burden. This intended qualitative study will illustrate the experiences of informal carers of individuals with KF who are accessing CM. It will assist in outlining the unmet support needs of these individuals to appraise future growth of a psychosocial intervention (Carswell et al. 2021b). The concept of LP is also related to caregivers and family members included providing any care delivery with the individual living with KD (Kalantar-Zadeh et al. 2021).

CONCLUSION

This chapter has outlined the emotional challenges that individuals may present with whilst living with CKD and KRT. It explored the importance of emotional well-being and identified means of support for them and their partners, families, and caregivers. Nurses and other members of the MDT must enable persons living with KD to learn to adapt to their treatment modalities in their life journey whilst living with this long-term illness. There must be clear, appropriate care pathways. Positive partnerships with individuals and their partners, families, and caregivers can foster increased shared decision-making and self-management. Persons living with KD do require emotional support from their health-care team, and it is important to acknowledge and act upon this from the initial diagnosis right through the trajectory of KD.

Emotional well-being is a crucial factor for individuals to live well with their long-term illness. Individuals must be enabled to reach their own ‘Holy Grail’ as identified in this patient advocate excerpt as below:

The ‘Holy Grail’ for most people with a chronic disease is to reclaim what is often lost in the face of a long-term condition: hope; empowerment; independence; control and well-being; but for most of us, reclaiming what is lost in our daily lives – often without or outside of the support of the healthcare system – is a mammoth struggle with no guarantee of success.

... when given the right support, tailored to each individual living with a chronic health condition, we can be empowered to reclaim as much control, health, and well-being in our lives as we are able – despite the very significant burden that living with such a condition may entail.

Jonathon Hope, MBE (Gair et al, 2019: 4).

REFERENCES

- Aitken, E., Ashby, H., Ashby, D., et al. (2023). *UK Kidney Association Clinical Practice Guideline. Vascular Access for Haemodialysis*. <https://ukkidney.org/sites/renal.org/files/FINAL%20FORMAT%20Vascular%20access%20for%20haemodialysis%20April%202023.pdf> (accessed 3 April 2023)
- Al-Ali, F., Elshirbeny, M., Hamad, A., et al. (2021). Prevalence of depression and sleep disorders in patients on dialysis: A cross-sectional study in Qatar. *International Journal of Nephrology* May 26; 2021: 5533416. <https://doi.org/10.1155/2021/5533416>
- Al-Aly, Z., Agarwal, A., Alwan, N., et al. (2023). Long COVID: long-term health outcomes and implications for policy and research. *Nature Reviews Nephrology* 19 (1): 1–2. <https://doi.org/10.1038/s41581-022-00652-2>
- Ali, H., Soliman, K., Mohamed, M.M., et al. (2021). The effects of dialysis modality choice on cognitive functions in patients with end-stage renal failure: a systematic review and meta-analysis. *International Urology Nephrology* 53 (1):155–163. <https://doi.org/10.1007/s11255-020-02603-x>
- Alhawattmeh, H., Alshammari, S., Rababah, J.A. (2022). Effects of mindfulness meditation on trait mindfulness, perceived stress, emotion regulation, and quality of life in hemodialysis patients: A randomized controlled trial. *International Journal of Nursing*

- Sciences* 9 (2): 139–146. <https://doi.org/10.1016/j.ijnss.2022.03.004>
- Almutary, H. (2022). Depression, sleep disturbance, and quality of life in patients undergoing dialysis therapy. *Applied Nursing Research* 67: 151610. <https://doi.org/10.1016/j.apnr.2022.151610>
- Al Naamani, Z., Gormley, K., Noble, H., et al. (2021). Fatigue, anxiety, depression, and sleep quality in patients undergoing haemodialysis. *BMC Nephrology* 22 (1): 1–8. <https://doi.org/10.1186/s12882-021-02349-3>
- American Association of Kidney Patients (2019). Decade of the Kidney. <https://aakp.org/center-for-patient-engagement-and-advocacy/decade-of-the-kidney/> (accessed 20 March 2023)
- Andrews, P., Burnapp, L. (2018). *British Transplantation/Renal Association. Guidelines for Living Donor Transplantation*. Fourth Edition. <https://ukkidney.org/sites/renal.org/files/Living-Donor.pdf> (accessed 10 April 2023)
- Antoun, J., Brown, D.J., Jones, D.J.W., et al. (2021). Understanding the impact of initial COVID-19 restrictions on physical activity, wellbeing, and quality of life in shielding adults with end-stage renal disease in the United Kingdom dialysing at home versus in-centre and their experiences with telemedicine. *International Journal Environmental Research Public Health* 18(6): 3144. <https://doi.org/10.3390/ijerph18063144>
- Ashby, D., Borman, N., Burton, J., et al. (2019). *UK Kidney Association Clinical Practice Guideline Haemodialysis*. <https://ukkidney.org/sites/renal.org/files/FINAL-HD-Guideline.pdf> (accessed 3 April 2023)
- Auer, J. (2008). Psychological perspectives. In: *Renal Nursing*. 3e (ed. N. Thomas), 73–102. Edinburgh: Balliere Tindall Elsevier
- Auguste, B.L., Bargman, J.M. (2022). Peritoneal dialysis prescription and adequacy in clinical practice: Core Curriculum 2023. *American Journal of Kidney Disease* 81 (1): 100–109. <https://doi.org/10.1053/j.ajkd.2022.07.004>
- Arday, S. (2022). Closing the gap: enhancing psychosocial care for people living with kidney disease. *Journal of Kidney Care* 7 (6): 264–268. <https://doi.org/10.12968/jkoc.2022.7.6.264>
- Baker, L.A., March, D.S., Wilkinson, T.J., et al. (2021). *UK Kidney Association Clinical Practice Guideline. Exercise and Lifestyle in CKD*. https://ukkidney.org/sites/renal.org/files/Exercise%20and%20Lifestyle%20in%20CKD%20clinical%20practice%20guide%20line33_v4_FINAL_0.pdf (accessed 3 April 2023)
- Baker, R., Mark, P., Patel, R. (2017). *UK Kidney Association. Clinical Practice Guideline Post-Operative Care in the Kidney Transplant Recipient*. <https://ukkidney.org/sites/renal.org/files/FINAL-Post-Operative-Care-Guideline-1.pdf> (accessed 31 March 2023)
- Banks, J., Bell, A., Chilcot, J., et al. (2020). Kidney disease and mental health. Statement of intent from the Centre for Mental Health and Kidney Research UK. <https://www.centreformentalhealth.org.uk/publications/kidney-disease-and-mental-health> (accessed 9 March 2023)
- Bayülgen, M.Y., Gün, M. (2022). Effect of complementary and integrative treatments on fatigue symptoms in hemodialysis patients: A systematic review. *Holistic Nursing Practice* 36 (1): 17–27, January/February. <https://doi.org/10.1097/HNP.0000000000000489>
- Bazrafshan, F.D., Darvizeh, Z., Banijamali, S.S. (2023). The relationship between hemodialysis patients' treatment adherence, procrastination, and difficulty in emotion regulation: A cross-sectional study in southeast Iran. *Frontiers in Psychology* 13: 1041912. <https://doi.org/10.3389/fpsyg.2022.1041912>
- Beaumier, M., Calvar, E., Launay, L., et al. (2022). Effect of social deprivation on peritoneal dialysis uptake: A mediation analysis with the data of the REIN registry. *Peritoneal Dialysis International* 42 (4): 361–369. <https://doi.org/10.1177/08968608211023268>
- Bello, A.K., Okpechi, I.G., Osman, M.A., et al. (2022a). Epidemiology of haemodialysis outcomes. *Nature Reviews Nephrology* 18, 378–395. <https://doi.org/10.1038/s41581-022-00542-7>
- Bello, A.K., Okpechi, I.G., Osman, M.A., et al. (2022b). Epidemiology of peritoneal dialysis outcomes. *Nature Reviews Nephrology* 18: 779–793. <https://doi.org/10.1038/s41581-022-00623-7>
- Bennett, P.N., Bohm, C., Harasemiw, O., et al. (2022). Physical activity and exercise in peritoneal dialysis: International Society for Peritoneal Dialysis and the Global Renal Exercise Network practice recommendations. *Peritoneal Dialysis International* 42 (1): 8–24. <https://doi.org/10.1177/08968608211055290>
- Bikbov, B., Purcell, C.A., Levey, A.S., et al. (2020). Global, regional, and national burden of chronic kidney disease, 1990–2017: A systematic analysis for the Global Burden of Disease Study. *Lancet* 395 (10225): 709–733. [https://doi.org/10.1016/s0140-6736\(20\)30045-3](https://doi.org/10.1016/s0140-6736(20)30045-3)
- Blake, P.G., Brown, E.A. (2020). Person-centered peritoneal dialysis prescription and the role of shared decision-making. *Peritoneal Dialysis International* 40 (3): 302–309. <https://doi.org/10.1177/0896860819893803>
- Bonenkamp, A.A., Druiventak, T.A., van Eck van der Sluijs, A., et al. (2021). The impact of COVID-19 on the mental health of dialysis patients. *Journal of Nephrology* 34: 337–344. <https://doi.org/10.1007/s40620-021-01005-1>
- Boonstra, M.D., Reijneveld, S.A., Foitzik, E.M., et al. (2021). How to tackle health literacy problems in chronic kidney disease patients? A systematic review to identify promising intervention targets and strategies. *Nephrology Dialysis Transplantation* 36 (7): 1207–1221. <https://doi.org/10.1093/ndt/gfaa273>
- Bossola, M., Pepe, G., Marzetti, E. (2017). Editorial. Health-related quality of life of patients on chronic dialysis: The need for a focused effort. *Seminars in Dialysis* 30: 413–416. <https://doi.org/10.1111/sdi.12620>
- Burns, T., Fernandez, R., Stephens, M. (2017). The experience of waiting for a kidney transplant: A qualitative study. *Journal of Renal Care* 43 (4): 247–255. <https://doi.org/10.1111/jorc.12209>
- Brown, E.A., Blake, P.G., Boudville, N., et al. (2020). International Society for Peritoneal Dialysis practice recommendations: Prescribing high-quality goal-directed peritoneal dialysis. *Peritoneal Dialysis International* 40 (3): 244–253. <https://doi.org/10.1177/0896860819895364>
- Brown, E.A., Ekstrand, A., Gallieni, M., et al. (2022). Availability of assisted peritoneal dialysis in Europe: call for increased and equal

- access, *Nephrology Dialysis Transplantation* 37 (11): 2080–2089. <https://doi.org/10.1093/ndt/gfac193>
- Brys, A.D.H., Bossola, M., Lenaert, B., et al. (2020). Daily physical activity in patients on chronic haemodialysis and its relation with fatigue and depressive symptoms. *International Urology and Nephrology* 52 (10): 1959–1967. <https://doi.org/10.1007/s11255-020-02578-9>
- Carswell, C., Reid, J., Walsh, I., et al. (2019). Implementing an arts-based intervention for patients with end-stage kidney disease whilst receiving haemodialysis: A feasibility study protocol. *Pilot Feasibility Stud* 5 (1). <https://doi.org/10.1186/s40814-018-0389-y>
- Carswell, C., Reid, J., Walsh, I., et al. (2021a). The experiences of a complex arts-based intervention for patients with end-stage kidney disease whilst receiving haemodialysis: a qualitative process evaluation. *Healthcare (Basel)* 9 (10) : 1392. <http://doi.org/10.3390/healthcare9101392>
- Carswell, C., Yaqoob, M., Gilbert, P., et al. (2021b). Exploration of caregiver experiences of conservatively managed end-stage kidney disease to inform development of a psychosocial intervention: The ACORN stud protocol. *Healthcare* 9: 1731. <https://doi.org/10.3390/healthcare9121731>
- Carswell, C., Cogley, C., Branham, K., et al. (2023). Chronic kidney disease and severe mental illness: a scoping review. *Journal of Nephrology*. <https://doi.org/10.1007/s40620-023-01599-8>
- Carter, S.A., Gutman, T., Logeman, C., et al. (2020). Identifying outcomes important to patients with glomerular disease and their caregivers. *Clinical Journal of the American Society of Nephrology* 15 (5): 673–684. <http://doi.org/10.2215/CJN.13101019>
- Caskey, F., Dreyer, G., Evans, K., et. al. (2018). *Kidney health inequalities in the United Kingdom: Reflecting on the past, reducing in the future*. Peterborough: Kidney Research UK. https://www.kidneyresearchuk.org/wp-content/uploads/2019/02/Health_Inequalities_Report_Complete_FINAL_Web_20181017.pdf (accessed 17 March 2023)
- Castledine, C.I., Gilg, J.A., Rogers, C., et al. (2013). Renal centre characteristics and physician practice patterns associated with home dialysis use, *Nephrol Dial Transplant* 28 (8): 2169–2180. <https://doi.org/10.1093/ndt/gft196>
- Cavanaugh, K.L., Wingard, R.L., Hakim, R.M., et al. (2010). Low health literacy associates with increased mortality in ESRD. *Journal of the American Society of Nephrology* 21 (11): 1979–1985. <https://doi.org/10.1681/ASN.2009111163>
- Centers for Disease Control and Prevention (2020). Healthy People 2030: What Is Health Literacy? <https://www.cdc.gov/healthliteracy/learn/index.html> (accessed 27 March 2023)
- Centre for Mental Health and Kidney Research UK (2023). Addressing the mental health challenges of life with kidney disease: The case for change. https://www.kidneyresearchuk.org/wp-content/uploads/2023/05/CentreforMHKRUK_TheCaseForChange.pdf (accessed 31 August 2023)
- Chadban, S.J., Ahn, C., Axelrod, D.A., et al. (2020). Summary of the Kidney Disease: Improving Global Outcomes (KDIGO) Clinical Practice Guideline on the evaluation and management of candidates for kidney transplantation. *Transplantation* 104 (4): 708–714. <https://doi.org/10.1097/TP.0000000000003137>
- Chang, C., Hayes, R., Perera, G., et al. (2011). Life expectancy at birth for people with serious mental illness and other major disorders from a secondary mental healthcare case register in London. *Plos ONE* 6 (5): e19590. <https://doi.org/10.1371/journal.pone.0019590>
- Cheetham, M.S., Wilkie, M., Loud, F., et al. (2022). Establishing a core outcome measure for life participation in patients receiving peritoneal dialysis: A standardised outcomes in nephrology–peritoneal dialysis consensus workshop report. *Peritoneal Dialysis International* 42 (6): 562–570. <https://doi.org/10.1177/08968608221096560>
- Chou, J., Kiebalo, T., Jagiello, P., et al. (2021). Multifaceted sexual dysfunction in dialyzing men and women: pathophysiology, diagnostics, and therapeutics. *Life* 11(4): 311. <https://doi.org/10.3390/life11040311>
- Cogley, C., Carswell, C., Bramham, K., et al. (2022). Chronic kidney disease and severe mental illness: Addressing disparities in access to healthcare and health outcomes. *Clinical Journal of the American Society of Nephrology* 17 (9): 1413–1417. <https://doi.org/10.2215/cjn.15691221>
- Cogley, C., Bramham, J., Bramham, K., et al. (2023a). High rates of psychological distress, mental health diagnoses and suicide attempts in people with CKD in Ireland. *Nephrology Dialysis Transplantation*. <https://doi.org/10.1093/ndt/gfad021>
- Cogley, C., Carswell, C., Bramham, J., et al. (2023b). Improving kidney care for people with severe mental health difficulties: a thematic analysis of twenty-two healthcare providers' perspectives. *Front. Public Health* 11: 1225102. <https://doi.org/10.3389/fpubh.2023.1225102>
- Collister, D., Saad, N., Christie, E., et al. (2021). Providing care for transgender persons with kidney disease: A narrative review. *Canadian Journal of Kidney Health and Disease* 20 (8). <https://doi.org/10.1177/2054358120985379>
- Cossart, A.R., Staatz, C.E., Isbel, N.M., et al. (2022). Exploring transplant medication-taking behaviours in older adult kidney transplant recipients: a qualitative study of semi-structured interviews. *Drugs & Aging* 39 (11): 887–898. <https://doi.org/10.1007/s40266-022-00975-6>
- Coyne, E., Fretwell, S. (2022). What is psychosocial care, and why is it important for renal patients? *Journal of Kidney Care* 7 (6): 288–292. <https://doi.org/10.12968/jokc.2022.7.6.288>
- Crowe, K., Quinn, T.J., Mark, P.B., et al. (2021). “Is It removed during dialysis?”—Cognitive dysfunction in advanced kidney failure—A review article. *Frontiers in Neurology* 12: 787370. <https://doi.org/10.3389/fneur.2021.787370>
- Danovitch, G.M. (2010a). Options for patients with advanced kidney disease. In: *Handbook of Kidney Transplantation*. 5e (ed Danovitch, G.), 1–18. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins

- Danovitch, I. (2010b). Psychiatric aspects of kidney transplantation. In: *Handbook of Kidney Transplantation*, 5e (ed. Danovitch, G.), 389–408. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins
- Danovitch, G.M. (2017). Options for patients with end-stage renal disease. In: *Handbook of Kidney Transplantation*, 6e (ed. Danovitch, G.), 1–20. Philadelphia: Wolters Kluwer
- Davis, S., Mohan, S. (2022). Managing patients with failing kidney allograft: many questions remain. *Clinical Journal of the American Society of Nephrology* 17 (3): 444–451. <https://doi.org/10.2215/CJN.14620920>
- Davison, S.N., Tupala, B., Wasylynnuk, B.A., et al. (2019). Recommendations for the care of patients receiving conservative kidney management: focus on management of CKD and symptoms. *Clinical Journal of the American Society of Nephrology* 14(4): 626–634. <https://doi.org/10.2215/cjn.10510917>
- De Jong, R.W., Stel, V.S., Rahmel, A., et al. (2022). Patient-reported factors influencing the choice of their kidney replacement treatment modality. *Nephrol Dial Transplant* 37 (3): 477–488. <https://doi.org/10.1093/ndt/gfab059>
- DePasquale, C., Pistorio, M.L., Veroux, M., et al. (2020). Psychological and psychopathological aspects of kidney transplantation: A systematic review. *Frontiers in Psychiatry* 5 (11): 106. <https://doi.org/10.3389/fpsy.2020.00106>
- DePasquale, N., Cabacungan, A., Ephraim, P.L., et al. (2019). Family members' experiences with dialysis and kidney transplantation. *Kidney Medicine* 1 (4): 171–179. <https://doi.org/10.1016/j.xkme.2019.06.001>
- Divyaveer, S., Jha, V. (2021). COVID-19 and care for patients with chronic kidney disease: Challenges and lessons. *FASEB Bioadv* 3 (8): 569–576. <https://doi.org/10.1096/fba.2021-00002>
- Duncanson, E., Chur-Hansen, A., Jesudason, S. (2021). Patient perspectives of coping with automated peritoneal dialysis. *Peritoneal Dialysis International* 42 (4): 344–352. <https://doi.org/10.1177/08968608211043411>
- Dziubek, W., Pawlaczyk, W., Rogowski, L., et al. (2021). Assessment of depression and anxiety in patients with chronic kidney disease and after kidney transplantation—a comparative analysis. *International Journal Environmental Research Public Health* 18 (19): 10517. <https://doi.org/10.3390/ijerph181910517>
- Edwards, D., Manera, K. (2022). Life participation: When there is more to life than dialysis. *Peritoneal Dialysis International* 42 (6): 552–553. <http://doi.org/10.1177/08968608221134680>
- Elwyn, G., Durand, M.A., Song, J., et al. (2017). A three-talk model for shared decision making: multistage consultation process. *BMJ* Nov 6; 359: j4891. <https://doi.org/10.1136/bmj.j4891>
- Ethier, I., Cho, Y., Hawley, C., et al. (2020). Effect of patient- and center-level characteristics on uptake of home dialysis in Australia and New Zealand: a multicenter registry analysis. *Nephrol Dial Transplant* 35 (11): 1938–1949. <https://doi.org/10.1093/ndt/gfaa002>
- European Food Banks Federation (2023). <https://www.eurofoodbank.org/> (accessed 17 September 2023)
- European Kidney Health Alliance (2021). *Call to action. Improving prevention, treatment & care of chronic kidney disease in the aftermath of COVID-19*. https://ekha.eu/wp-content/uploads/EKHA_call-to-action-to-tackle-CKD-at-EU-level-1.pdf (accessed 7 April 2023)
- Fernandez, L., Thompson, S., Berendonk, C., et al. (2022). Mental health care for adults treated with dialysis in Canada: A scoping review. *Canadian Journal of Kidney Health and Disease* 23; 9: 20543581221086328. <https://doi.org/10.1177/20543581221086328>
- Ferreira, T.L., Ribeiro, H.S., Ribeiro, A.L.A., et al. (2021). Exercise interventions improve depression and anxiety in chronic kidney disease patients: a systematic review and meta-analysis. *International Urology and Nephrology* 53 (5): 925–933. <https://doi.org/10.1007/s11255-020-02612-w>
- Finderup, J., Jensen, J.D., Lomborg, K. (2021). Shared decision-making in dialysis choice has potential to improve self-management in people with kidney disease: A qualitative follow-up study. *Journal of Advanced Nursing* 77 (4): 1878–1887. <https://doi.org/10.1111/jan.14726>
- Fissell, R.B., Schlundt, D., Cavanaugh, K.L., et al. (2021). A cross-sectional study of fixed and growth mindset in adult peritoneal dialysis patients. *Journal of Patient Experience* Nov 17; 8. <https://doi.org/10.1177/23743735211055289>
- Foreman, K.J., Marquez, N., Dolgert, A., et al. (2018). Forecasting life expectancy, years of life lost, and all-cause and cause-specific mortality for 250 causes of death: reference and alternative scenarios for 2016–40 for 195 countries and territories. *Lancet* 392 (10159): 2052–2090. [https://doi.org/10.1016/S0140-6736\(18\)31694-5](https://doi.org/10.1016/S0140-6736(18)31694-5)
- Gair, R.M., Stannard, C., Wong, E., et al. (2019). “Think Kidneys” transforming participation in chronic kidney disease. Programme Report. <https://www.thinkkidneys.nhs.uk/ckd/wp-content/uploads/sites/4/2019/01/Transforming-Participation-in-Chronic-Kidney-Disease-1.pdf> (accessed 7 April 2023)
- Ghahramani, N., Chinchilli, V.M., Kraschnewski, J.L., et al. (2022). Improving caregiver burden by a peer-led mentoring program for caregivers of patients with chronic kidney disease: randomized controlled trial. *Journal of Patient Experience* 9. <https://doi.org/10.1177/23743735221076314>
- Gerogianni, G., Babatsikou, F., Polikandrioti, M., et al. (2019). Management of anxiety and depression in haemodialysis patients: the role of non-pharmacological methods. *International Urology and Nephrology* 51 (1): 113–118. <https://doi.org/10.1007/s11255-018-2022-7>
- Gonzalez, A.M., Gutman, T., Lopez-Vargas, P., et al. (2020). Patient and caregiver priorities for outcomes in CKD: a multinational nominal group technique study. *American Journal of Kidney Disease* 76: 679–689. <https://doi.org/10.1053/j.ajkd.2020.03.022>
- Goodman, M.L., Molldrem, S., Elliott, A., et al. (2023). Long COVID and mental health correlates: a new chronic condition fits existing patterns. *Health Psychology Behavioral Medicine*. Jan 8; 11 (1): 2164498. <https://doi.org/10.1080/21642850.2022.2164498>

- Guthrie, G.D., Bell, S. (2019). Deprivation and kidney disease – a predictor of poor outcomes. *Clinical Kidney Journal* 13 (2): 128–132. <https://doi.org/10.1093/ckj/sfz151>
- Graham-Brown, M.P.M., Smith, A.C., Greenwood, S.A. (2022). Digital health interventions in chronic kidney disease: levelling the playing field? *Clinical Kidney Journal* 16 (5): 763–767. <https://doi.org/10.1093/ckj/sfac259>
- Gregg, L.P., Hedayati, S.S. (2020). Screening for depression in people with kidney failure. *CJASN* 15 (12): 1702–1704. <https://doi.org/10.2215/CJN.16381020>
- Gregg, L.P., Trombello, J.M., McAdams, M., et al. (2021). Diagnosis and management of depression in patients with kidney disease. *Seminars in Nephrology* 41 (6): 505–515. <https://doi.org/10.1016/j.semnephrol.2021.10.003>
- Griffin, S., Asgari, E., Sharif, A., et al. on behalf of the British Transplantation Society (2023). UK Guideline for the management of the patient with a failing kidney transplant. <https://bts.org.uk/uk-guideline-for-the-management-of-the-patient-with-a-failing-kidney-transplant> (accessed 26 September 2023)
- Grossi, A.A., Sever, M.S., Helleman, R. (2023). The 3-Step Model of informed consent for living kidney donation: a proposal on behalf of the DESCaRTES Working Group of the European Renal Association. *Nephrol Dial Transplant* 38 (7): 1613–1622. <https://doi.org/10.1093/ndt/gfad022>
- Hao, W., Tang, Q., Huang, X., et al. (2021). Analysis of the prevalence and influencing factors of depression and anxiety among maintenance dialysis patients during the COVID-19 pandemic. *International Urology and Nephrology* 53: 1453–1461. <https://doi.org/10.1007/s11255-021-02791-0>
- Hanson, C.S., Craig, J.C., Logeman, C., et al. (2020). Establishing core outcome domains in paediatric kidney disease: report of the standardized outcomes in nephrology-children and adolescents (SONG-KIDS) consensus workshops. *Kidney International* 98 (3): 553–565. <https://doi.org/10.1016/j.kint.2020.05.054>
- Harrison, T.G., Skrtic, M., Verdin, N.E., et al. (2020). Improving sexual function in people with chronic kidney disease: A narrative review of an unmet need in nephrology research. *Canadian Journal of Kidney Health and Disease* 4; 7: 2054358120952202. <https://doi.org/10.1177/2054358120952202>
- Henderson, M.D., McCurry, I.J., Deatrck, J.A., et al. (2022). Experiences of adult men who are homeless accessing care: A qualitative study. *Journal of Transcultural Nursing*. Mar; 33 (2): 199–207. <https://doi.org/10.1177/10436596211057895>
- Her Majesty Government/ Department of Health (2011). *No Health Without Mental Health: A Cross-Government Mental Health Outcomes Strategy for People of All Ages*. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/213761/dh_124058.pdf (accessed 5 April 2023)
- Hersh-Rifkin, M. (2010). Psychosocial and financial aspects of transplantation. In: *Handbook of Kidney Transplantation*. 5e (ed. Danovitch, G.), 432–440. Philadelphia: Wolters Kluwer Lippincott Williams & Wilkins
- Hersh-Rifkin, M. (2017). Psychosocial and financial aspects of transplantation. In: *Handbook of Kidney Transplantation*. 6e (ed. Danovitch, G.), 538–549. Philadelphia: Wolters Kluwer
- Hope, J. (2012). Call for action on mental and emotional health. *Journal of Renal Nursing* 4 (1): 5
- Howell, M., Wong, G., Turner, R.M., et al. (2016). The consistency and reporting of quality-of-life outcomes in trials of immunosuppressive agents in kidney transplantation: a systematic review and meta-analysis. *American Journal of Kidney Diseases* 67: 762–774. <https://doi.org/10.1053/j.ajkd.2015.11.006>
- Hsaio, L.L., Shah, K.M., Liew, A., et al. (2023). Kidney health for all: preparedness for the unexpected in supporting the vulnerable. *Kidney International* 103: 436–443. <https://doi.org/10.1016/j.kint.2022.12.013>
- Hussein, W.F., Bennett, P.N., Abra, G., et al. (2022). Integrating patient activation into dialysis care. *American Journal of Kidney Diseases* 79 (1): 105–112. <https://doi.org/10.1053/j.ajkd.2021.07.015>
- Ibrahim, N., Michail, M., Callaghan, P. (2014). The strengths-based approach as a service delivery model for severe mental illness: a meta-analysis of clinical trials. *BMC Psychiatry* 14 (1): 243. <https://doi.org/10.1186/s12888-014-0243-6>
- Imeri, H., Holmes, E., Desselle, S., et al. (2021). The Impact of the COVID-19 Pandemic on Self-Reported Management of Chronic Conditions. *Journal of Patient Experience* 8. <https://doi.org/10.1177/23743735211007693>
- Iwagami, M., Mansfield, K.E., Hayes, J.F., et al. (2018). Severe mental illness and chronic kidney disease: a cross-sectional study in the United Kingdom. *Clinical Epidemiology* 10: 421–429. <https://doi.org/10.2147/CLEP.S154841>
- Iyasere, O., Okai, D., Brown, E. (2017). Cognitive function and advanced kidney disease: longitudinal trends and impact on decision-making. *Clinical Kidney Journal*. <https://doi.org/10.1093/ckj/sfw128>
- Johansen, K. (2020). Sexual dysfunction in chronic kidney disease. In *Chronic Renal Disease*. 2e (ed. PL Kimmel, ME Rosenberg), 593–611. Cambridge, MA: Academic Press. <https://doi.org/10.1016/B978-0-12-815876-0.00037-1>
- Jones, J. (2020). Depression: A side effect of CKD. *CJASN* 15: 1692–1693. <https://doi.org/10.2215/CJN.16411020>
- Josephson, M.A., Becker, Y., Budde, K., et al. (2023). Challenges in the management of the kidney allograft: from decline to failure: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. *Kidney International*. <https://doi.org/10.1016/j.kint.2023.05.010>
- Ju, A., Josephson, M.A., Butt, Z. et al. (2019). Establishing a core outcome measure for life participation: A standardized outcomes in nephrology-kidney transplantation consensus workshop report. *Transplantation* 103 (6): 1199–1205. <https://doi.org/10.1097/TP.0000000000002476>
- Kalantar-Zadeh, K., Kam-Tao, Li P., Tantisattamo, E., et al. (2021). Living well with kidney disease by patient and care-partner

- empowerment: kidney health for everyone everywhere. *Kidney International* 99 (2): 278–284. <https://doi.org/10.1016/j.kint.2020.11.004>
- Kharbanda, K., Iyasere, O., Caskey, F., et al. (2020). *UK Kidney Association. Commentary on the NICE Guideline on Renal Replacement Therapy and Conservative Management*. <https://ukkidney.org/sites/renal.org/files/Commentary-on-the-NICE-Guideline-on-RRT-and-conservative-management.pdf> (accessed 3 April 2023)
- Kidney Care UK (2022a). *Cost of staying alive report 2022. Executive summary*. https://www.kidneycareuk.org/documents/794/Cost_of_Staying_Alive_Report_Web.pdf (accessed 31 August 2023)
- Kidney Care UK (2022b). *Foodbanks, fuel banks and social and community shopping*. <https://www.kidneycareuk.org/get-support/cost-living-hub/food-banks-fuel-banks-and-social-and-community-shopping> (accessed 21 March 2023)
- Kidney Care UK (2023a). *Left out in the cold report 2023*. https://www.kidneycareuk.org/documents/931/Left_Out_in_the_Cold_Kidney_Care_UK_Report_July_2023_Mbg0u3r.pdf (accessed 31 August 2023)
- Kidney Care UK (2023b). *Building your emotional resilience*. <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/building-your-emotional-resilience> (accessed 6 April 2023)
- Kidney Care UK and National Psychosocial Working Group (2022). *Psychosocial Health – a manifesto for action*. Alton: Kidney Care UK. <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/mental-health/manifesto/> (accessed 27 February 2023)
- Kidney Disease Improving Global Outcomes (KDIGO) (2017). *Managing your adult patients who have a kidney transplant*. (Online) <https://kdigo.org/guidelines/transplant-recipient/managing-your-adult-patients-who-have-a-kidney-transplant-kdigo/> (accessed 25 March 2023)
- Kidney Research UK (2019). *Kidney health inequalities in the UK. An agenda for change*. Peterborough: Kidney Research UK. https://www.kidneyresearchuk.org/wp-content/uploads/2019/09/Health_Inequalities_lay_report_FINAL_WEB_20190311.pdf (accessed 17 March 2023)
- Kidney Research UK (2022). *Survey reveals impact on kidney patients' mental health – time for action*. <https://www.kidneyresearchuk.org/2022/02/23/survey-reveals-impact-on-kidney-patients-mental-health-time-for-action/> (accessed 13 March 2023)
- Kidney Research UK (2023). *Kidney disease: A UK public health emergency. The health economics of kidney disease to 2023*. https://www.kidneyresearchuk.org/wp-content/uploads/2023/06/Economics-of-Kidney-Disease-full-report_accessible.pdf (accessed 31 August 2023)
- Kim, H., Jeong, I.S., Cho, M.K. (2022). Effect of treatment adherence improvement program in hemodialysis patients: A systematic review and meta-analysis. *International Journal of Environmental Research and Public Health* 19 (18): 11657. <https://doi.org/10.3390/ijerph191811657>
- Kondo, K., Antick, J.R., Ayers, C.K., et al. (2020). Depression screening tools for patients with kidney failure: A systematic review. *CJASN* 12: 1785–1795. <https://doi.org/10.2215/CJN.05540420>
- Krishnan, A., Teixeira-Pinto, A., Lim, W.H., et al. (2020). Health-related quality of life in people across the spectrum of CKD. *Kidney International Reports* 5: 2264–2274. <https://doi.org/10.1016/j.ekir.2020.09.028>
- Krishnasamy, R., Gray, N.A. (2018). Low socio-economic status adversely effects dialysis survival in Australia. *Nephrology* 23: 453–460. <https://doi.org/10.1111/nep.13053>
- Kroenke, K., Spitzer, R.L., Williams, J.B. et al. (2009). An ultra brief screening scale for anxiety and depression-the PHQ-4. *Psychosomatics* 50 (6): 613–621
- Ladin, K., Porteny, T., Perugini, J.M., et al. (2021). Perceptions of telehealth vs in-person visits among older adults with advanced kidney disease, care partners, and clinicians. *JAMA Netw Open* 4 (12): e2137193. <https://doi.org/10.1001/jamanetworkopen.2021.37193>
- Lai, Y.L., Neo, H.L.M., Vathsala, A., et al. (2020). Comparing emotional adjustment of living-donor and deceased-donor kidney transplant patients. *Transplantation Direct* 6 (2): e529. <https://doi.org/10.1097/TXD.0000000000000956>
- Lameire, N., Vanholder, R. (2020). Health literacy problems of kidney patients. *Nephrology Dialysis Transplantation* 36 (7): 1155–1147. <http://doi.org/10.1093/ndt/gfaa340>
- Langham, R.G., Kalantar-Zadeh, K., Bonner, A., et al. (2022). World Kidney Day Joint Steering Committee. Kidney health for all: bridging the gap in kidney health education and literacy. *Nephrology Dialysis Transplantation* 37 (4): 605–612. <https://doi.org/10.1093/ndt/gfac038>
- Lee, J., Steel, J., Roumelioti, M.E., et al. (2020). Psychosocial impact of COVID-19 pandemic on patients with end-stage kidney disease on hemodialysis. *Kidney360* 1: 1390–1397. <https://doi.org/10.34067/KID.0004662020>
- Leeies, M., Collister, D., Ho, J., et al. (2023). Inequities in organ and tissue donation and transplantation for sexual orientation and gender identity diverse people: A scoping review. *American Journal of Transplantation*. March 28: S1600–6135(23)00359-3. <https://doi.org/10.1016/j.ajt.2023.03.016>
- Lemieux, I. (2004). Sexuality in palliative care : patient perspectives. *Palliative Medicine* 18: 630–637
- Lentine, K.L., Kasiske, B.L., Levey, A.S., et al. (2017). KDIGO Clinical Practice Guideline on the Evaluation and Care of Living Kidney Donors. *Transplantation*. Aug; 101 (8S Suppl 1): S1–S109. <https://doi.org/10.1097/TP.0000000000001769>
- Levey, A.S., Eckardt, K-U, Dorman, N.M., et al. (2021). Nomenclature for kidney function and disease: Executive summary and glossary from a Kidney Disease: Improving Global Outcomes (KDIGO) consensus conference. *Peritoneal Dialysis International* 41 (1): 5–14. <https://doi.org/10.1177/0896860820934730>
- Lev-Wiesel, R., Sasson, L., Scharf, N., et al. (2022). Losing faith in my body: Body image in individuals diagnosed with end-stage renal

- disease as reflected in drawings and narratives. *International Journal of Environmental Research and Public Health* 19, 10777. <https://doi.org/10.3390/ijerph191710777>
- Levy, J., Brown, E., Lawrence, A. (2016). *Oxford Handbook of Dialysis*, 4e, Oxford: Oxford University Press
- Lew, S.Q., Wallace, E.L., Srivatana, V., et al. (2021). Telehealth for home dialysis in COVID-19 and beyond: a perspective from the American Society of Nephrology COVID-19 Home Dialysis Subcommittee. *American Journal of Kidney Disease* 77 (1): 142–148. <https://doi.org/10.1053/j.ajkd.2020.09.005>
- Li, P.K., Garcia-Garcia, G., Lui, S.F., et al. (2020). Kidney health for everyone everywhere – from prevention to detection and equitable access to care. *Clinical Nephrology* 93 (3): 111–122. <https://doi.org/10.5414/CNWKDEditorial>
- Lightfoot, C.J., Nair, D., Bennett, P.N., et al. (2022a). Patient activation: The cornerstone of effective self-management in chronic kidney disease? *Kidney and Dialysis* 2: 91–105. <https://doi.org/10.3390/kidneydial2010012>
- Lightfoot, C.J., Wilkinson, T.J., Hadjiconstantinou, M., et al. (2022b). The codevelopment of “My Kidneys & Me”: A digital self-management program for people with chronic kidney disease. *Journal of Medical Internet Research* 24 (11): e39657. <https://doi.org/10.2196/39657>
- Lightfoot, C.J., Wilkinson, T.J., Yates, T., et al. (2022c). ‘Self-management intervention through lifestyle education for kidney health’ (the SMILE-K study): protocol for a single-blind longitudinal randomised controlled trial with nested pilot study. *BMJ Open*. Nov 16;12(11): e064916. <https://doi.org/10.1136/bmjopen-2022-064916>
- Lin, J., Ye, H., Yi, C., et al. (2020). The negative impact of depressive symptoms on patient and technique survival in peritoneal dialysis: a prospective cohort study. *International Urology Nephrology* 52 (12): 2393–2401. <https://doi.org/10.1007/s11255-020-02593-w>
- Locatelli, F., Del Vecchio, L. (2023). Quality of life: a crucial aspect for the patients, a neglected goal in the treatment of anemia in patients with CKD. *Kidney International* 103: 1025–1027. <https://doi.org/10.1016/j.kint.2023.03.026>
- Loud, F. (2022). Psychosocial care: we can do better. *Journal of Kidney Care* 7 (5): 212–215. <https://doi.org/10.12968/jokc.2022.7.5.212>
- Low, J.K., Williams, A., Manias, E., et al. (2015). Interventions to improve medication adherence in adult transplant recipients: a systematic review. *Nephrology Dialysis Transplantation* 30, 752–761. <https://doi.org/10.1093/ndt/gfu204>
- Lu, E., Chai, E. (2021). Kidney supportive care in peritoneal dialysis: Developing a person-centered kidney disease care plan. *Kidney Medicine* 4 (2): 100392. <https://doi.org/10.1016/j.xkme.2021.10.005>
- Maharjan, J. (2022). Psychological distress among patients receiving hemodialysis in a teaching hospital. *Journal of Patan Academy of Health Sciences*. 9 (3): 89–96. <https://doi.org/10.3126/jpahs.v9i3.52220>
- Magadi, W., Lightfoot, C.J., Memory, K.E., et al. (2022). Patient activation and its association with symptom burden and quality of life across the spectrum of chronic kidney disease stages in England. *BMC Nephrol* 23 (45). <https://doi.org/10.1186/s12882-022-02679-w>
- Manera, K.E., Johnson, D.W., Craig, J.C., et al. (2019a). Patient and caregiver priorities for outcomes in peritoneal dialysis. *Clinical Journal of the American Society of Nephrology* 14 (1): 74–83. <https://doi.org/10.2215/CJN.05380518>
- Manera, K.E., Tong, A., Craig, J.C., et al. (2019b). An international Delphi survey helped develop consensus-based core outcome domains for trials in peritoneal dialysis. *Kidney International* 96: 699–710. <https://doi.org/10.1016/j.kint.2019.03.015>
- Manera, K.E., Johnson, D.W., Craig, J.C., et al. (2020). SONG-PD workshop investigators. Establishing a core outcome set for peritoneal dialysis: Report of the SONG-PD (standardized outcomes in nephrology-peritoneal dialysis) consensus workshop. *American Journal of Kidney Disease* 75 (3): 404–412. <https://doi.org/10.1053/j.ajkd.2019.09.017>
- Matthews, M., Carswell, C., Redmond, A., et al. (2021). A nonrandomised pilot study to examine the feasibility and acceptability of reflexology in patients undergoing hospital-based haemodialysis (solitude study). *Journal of Renal Care* 47 (4): 255–264. <https://doi.org/10.1111/jorc.12372>
- Mayes, J., Billany, R.E., Vadasz, N., et al. (2021). The rapid development of a novel kidney specific digital intervention for self-management of physical activity and emotional well-being during the COVID-19 pandemic and beyond: Kidney beam. *Clinical Kidney Journal* 15 (3): 571–573. <http://doi.org/10.1093/ckj/sfab239>
- McCulloch, A., O’Leary, C. (2022). Should Psychotic Experience Contraindicate Organ Transplant? A Narrative Review. *Illness, Crisis & Loss*. <https://doi.org/10.1177/10541373221116748>
- McKeaveney, C., Noble, H., Carswell, C., et al. (2021). Psychosocial well-being of patients with kidney failure receiving haemodialysis during a pandemic: A survey. *Healthcare* 9: 1087. <https://doi.org/10.3390/healthcare9081087>
- McKeaveney, C., Noble, H., Courtney, A.E., et al. (2022). Dialysis, distress, and difficult conversations: Living with a kidney transplant. *Healthcare* 10: 1177. <https://doi.org/10.3390/healthcare10071177>
- McKeaveney, C., Witham, M., Alamrani, A.O., et al. (2023). Quality of life in advanced renal disease managed either by haemodialysis or conservative care in older patients. *BMJ Support Palliat Care* 13 (1): 87–94. <https://doi.org/10.1136/bmjspcare-2020-002237>
- Mencap. (2022). *Mental health*. <https://www.mencap.org.uk/learning-disability-explained/research-and-statistics/health/mental-health> (accessed 1 April 2023)
- Michie, S., Atkins, L., West, R. (2014). *The Behaviour Change Wheel: A Guide to Designing Interventions* (London: Silverback Publishing)
- Miller, W.R., Rollnick, S. (2009). Ten things that motivational interviewing is not. *Behavioural and Cognitive Psychotherapy*. 37: 129–140

- Miron, A., Stefan, A.E., Nistor, I., et al. (2023). The impact of renal transplantation on sexual function in males with end-stage kidney disease: a systematic review and meta-analysis. *International Urology and Nephrology* 55: 563–577. <https://doi.org/10.1007/s11255-022-03442-8>
- Mohottige, D., Lunn, M.R. (2019). Advancing equity in nephrology: Enhancing care for LGBTQ+ patients and our workforce. *Clinical Journal of the American Society of Nephrology* 14 (7): 1094–1096. <https://doi.org/10.2215/CJN.01950219>
- Mohottige, D., Lunn, M.R. (2020). Ensuring gender-affirming care in nephrology: Improving care for transgender and gender-expansive individuals. *Clinical Journal of the American Society of Nephrology* 15 (8): 1195–1197. <https://doi.org/10.2215/CJN.14471119>
- Mundt, J., Marks, I., Shear, M., et al. (2002). The Work and Social Adjustment Scale: A simple measure of impairing in functioning. *The British Journal of Psychiatry* 180 (5): 461–264. <https://doi.org/10.1192/bjp.180.5.461>
- Murphy, F. (2011). Managing post-transplant patients in primary care. *Practice Nursing* 22 (6): 292–297
- Murphy, F. (2012). Sexual concerns: living with end-stage renal disease. *Journal of Renal Nursing* 4 (1): 12–17
- Murphy, F. (2014). Psychological perspectives. In *Renal Nursing*, 4 e (ed. N. Thomas), 80–96. Oxford: Wiley Blackwell
- Murphy F. (2019). Psychological perspectives. In *Renal Nursing. Care and Management of People with Kidney Disease*. 5 e (ed. N. Thomas), 81–104. Oxford: Wiley Blackwell
- Murphy, F., Byrne, G. (2022a). Promoting kidney health in cardiovascular disease: part one. *British Journal of Cardiac Nursing* Nov 17 (10). <https://doi.org/10.12968/bjca.2022.0083>
- Murphy, F., Byrne, G. (2022b). Promoting kidney health in cardiovascular disease: part two. *British Journal of Cardiac Nursing* Dec 17 (12). <https://doi.org/10.12968/bjca.2022.0111>
- Nair, D., Cavanaugh, K.L. (2020) Measuring patient activation as part of kidney disease policy: Are we there yet? *Journal of American Society of Nephrology* 31 (7): 1435–1443. <https://doi.org/10.1681/ASN.2019121331>
- Natale, P., Palmer, S.C., Ruospo, M., et al. (2019). Psychosocial interventions for preventing and treating depression in dialysis patients. *Cochrane Database of Systematic Reviews* 12 (12): CD004542. <https://doi.org/10.1002/14651858.CD004542.pub3>
- National Comprehensive Cancer Network (2019). *NCCN Clinical Practice Guidelines in Oncology: Distress management*. v2.2019. http://www.nccn.org/professionals/physician_gls/distress.pdf (accessed 26 September 2023)
- National Health Service (NHS) England and the United Kingdom Renal Registry (2016). “Think Kidneys”. Tools for Change. Transforming participation in chronic kidney disease (CKD). <https://www.thinkkidneys.nhs.uk/ckd/tools-for-change/> (accessed 3 April 2023)
- National Institute for Health and Care Excellence (2018). *Renal replacement therapy and conservative management*. NICE guideline [NG107]. <https://www.nice.org.uk/guidance/ng107> (accessed 3 April 2023)
- National Institute for Health and Care Excellence (2021). *Chronic kidney disease: assessment and management*. NICE guideline [NG203]. <https://www.nice.org.uk/guidance/ng203> (accessed 3 April 2023)
- National Kidney Foundation (2021). Nephrologists need to ensure LGBTQ + patients receive affirming care. <https://www.kidney.org/newsletter/nephrologists-need-to-ensure-lgbtq-patients-receive-affirming-care> (accessed 28 March 2023)
- National Kidney Foundation (2023). Sexuality and kidney disease. <https://www.kidney.org/atoz/content/sexuality> (accessed 10 April 2023)
- Navaneethan, S.D., Vecchio, M., Johnson, D.W. et al. (2010). Prevalence and correlates of self-reported sexual dysfunction: A meta-analysis of observational studies. *American Journal of Kidney Diseases* 56 (4): 670–685
- Nelson, M.L., Buchanan-Pearl, K.R., Oribhabor, G.I., et al. (2020). Survival of the fittest: Addressing the disparities in the burden of chronic kidney disease. *Cureus* 12(7): e9499. <https://dpo.org/10.7759/cureus.9499>
- Neukirchinger, B., McLaughlin, L., Roberts, N. (2018). Social care and older people with chronic kidney disease: a mixed method narrative review. Bangor University/Wales Kidney Research Unit
- Norton, J.M., Eggers, P. (2020). Poverty and chronic kidney disease. In *Chronic Renal Disease*. 2e (ed. PL Kimmel, ME Rosenberg), 181–196. Cambridge, MA: Academic Press. <https://doi.org/10.1016/B978-0-12-815876-0.00013-9>
- Novick, T.K., Kushel, M., Crews, D. (2022). Unstable housing and kidney disease: A primer. *Kidney Medicine* 4 (4): 100443. <https://doi.org/10.1016/j.xkme.2022.100443>
- Ok, E., Kutlu, Y. (2021). The effect of motivational interviewing on adherence to treatment and quality of life in chronic hemodialysis patients: A randomized controlled trial. *Clinical Nursing Research* 30 (3): 322–333. <https://doi.org/10.1177/1054773820974158>
- Omerov, P., Craftman, Å.G., Mattsson, E., et al. (2020). Homeless persons’ experiences of health- and social care: A systematic integrative review. *Health & Social Care in the Community* 28 (1): 1–11. <https://doi.org/10.1111/hsc.12857>
- Ossareh, S., Tabrizian, S., Zebarjadi, M., et al. (2014). Prevalence of depression in maintenance haemodialysis patients and its correlation with adherence to medications. *Iranian Journal of Kidney Disease* 8 (6): 467–475
- Ozieh, M., Garacci, E., Campbell, J., et al. (2020). Adverse childhood experiences and decreased renal function: impact on all-cause mortality in U.S. adults. *American Journal of Preventive Medicine* 59 (2): e49–e57. <https://doi.org/10.1016/j.amepre.2020.04.005>

- Palmer, S., Vecchio, M., Craig, J.C., et al. (2013). Prevalence of depression in chronic kidney disease: systematic review and meta-analysis of observational studies. *Kidney International* 84 (1): 179–191. <https://doi.org/10.1038/ki.2013.77>
- Paremoer, L., Nandi, S., Serag, H., and Baum, F. (2021). Covid-19 pandemic and the social determinants of health. *BMJ* 372: n129. <https://doi.org/10.1136/bmj.n129>
- Pearce, C.J., Hall, N., Hudson, J.L., et al. (2023). Approaches to the identification and management of depression in people living with chronic kidney disease: A scoping review of 860 papers. *Journal of Renal Care*. 1–11. <https://doi.org/10.1111/jorc.12458>
- Perl, J., Brown, E.A., Chan, C.T., et al. (2023). Home dialysis: conclusion from a Kidney Disease: Improving Global Outcomes (KDIGO) controversies conference. *Kidney International* 103 (5): 842–858. <https://doi.org/10.1016/j.kint.2023.01.006>
- Pham, P-TT, Danovitch, G.M. (2017). Post-transplant: The first three months. In: *Handbook of Kidney Transplantation*. 6e (ed Danovitch, G.), 257–280. Philadelphia: Wolters Kluwer
- Porteny, T., Gonzales, K.M., Aufort, K.E., et al. (2022). Treatment decision-making for older kidney patients during COVID-19. *CJASN* 17 (7): 957–965. <https://doi.org/10.2215/CJN.13241021>
- Puchulu, M.B., Garcia-Fernandez, N., Landry, M.J. (2023). Food insecurity and chronic kidney disease: considerations for practitioners. *Journal of Renal Nutrition* 33 (5): 691–697. <https://doi.org/10.1053/j.jrn.2023.06.001>
- Pyrgidis, N., Mykoniatis, I., Tishukov, M., et al. (2021) Sexual dysfunction in women with end-stage renal disease: a systematic review and meta-analysis. *The Journal of Sexual Medicine* 18 (5): 936–945, <https://doi.org/10.1016/j.jsxm.2021.02.008>
- Queen's University Belfast (2016). *Renal Arts Group*. <https://www.qub.ac.uk/sites/renal-arts-group/> (accessed 3 April 2023)
- Radmore, N.M.T., Hyrkäs, K. (2019). Teaching-learning partnership between nurses and long-term patients undergoing peritoneal dialysis: A qualitative study. *Journal of Renal Care* 45 (3): 159–170. <https://doi.org/10.1111/jorc.12291>
- Raoofi, S., Pashazadeh, Kan F., Rafiei, S., et al. (2021) Hemodialysis and peritoneal dialysis-health-related quality of life: systematic review plus meta-analysis. *BMJ Support Palliat Care* July 22. <https://doi.org/10.1136/bmjspcare-2021-003182>
- Rhee, C.M., Edwards, D., Ahdoot, R.S., et al. (2022). Living well with kidney disease and effective symptom management: Consensus conference proceedings. *Kidney International Report* 7 (9): 1951–1963. <http://doi.org/10.1016/j.ekir.2022.06.015>
- Sautenet, B., Chapman, T.A.J.R., Warrens, A.N., et al. (2018). Range and consistency of outcomes reported in randomized trials conducted in kidney transplant recipients: a systematic review. *Transplantation* 102: 2065–2071. <https://doi.org/10.1097/tp.0000000000002278>
- Seekles, M., Ormandy, P., Kamerāde, D. (2020). Examining patient distress and unmet need for support across UK renal units with varying models of psychosocial care delivery: a cross-sectional survey study. *BMJ Open* 10 (9). <https://doi.org/10.1136/bmjopen-2020-036931>
- Sharp, S., Loud, F. (2020). 'Worried sick'—The impact of COVID-19 on people living with kidney disease: Findings from a patient survey. *Journal of Kidney Care* 5 (4): 176–179. <https://doi.org/10.12968/jokc.2020.5.4.176>
- Shenoy, A., Danovitch, I. (2017). Psychiatric aspects of kidney transplantation. In: *Handbook of Kidney Transplantation*. 6e (ed Danovitch, G.), 492–510. Philadelphia: Wolters Kluwer
- Shiels, P. (2003). Sexuality and the older person. *The World of Irish Nursing* 13: 31–32
- Siddiqi, N., Doran, T., Prady, S.L., et al. (2017). Closing the mortality gap for severe mental illness: are we going in the right direction? *British Journal of Psychiatry* 211 (3): 130–131. <https://doi.org/10.1192/bjp.bp.117.203026>
- Silva, D.M., Silva, RMCRA, Pereira, E.R., et al. (2018). The body marked by the arteriovenous fistula: a phenomenological point of view. *Revista Brasileira de Enfermagem* 71 (6): 2869–2875. <http://dx.doi.org/10.1590/0034-7167-2017-0898>
- Soliva, M.S., Salvador, I.R., Testal, A.G., et al. (2022). Intervention study to verify the effect of live classic music during hemodialysis on the quality of life of patients with chronic kidney disease. *Nefrologia (Engl Ed)*. 42 (5): 559–567. <https://doi.org/10.1016/j.nefro.2021.07.010>
- Standardised Outcomes in Nephrology (SONG) Initiative (2017). *The SONG Handbook: for establishing and implementing core outcomes in clinical trials across the spectrum of Chronic Kidney Disease*. Version 1.0. June 2017, Sydney, Australia. <https://songinitiative.org/reports-and-publications/> (accessed 30 March 2023)
- Standardised Outcomes in Nephrology (SONG) Initiative (2023). *The SONG Initiative*. <https://songinitiative.org> (accessed 30 March 2023)
- Subramanian, L., Kirk, R., Cuttitta, T., et al. (2019). Remote management for peritoneal dialysis: a qualitative study of patient, care partner, and clinician perceptions and priorities in the United States and the United Kingdom. *Kidney Medicine* 1 (6): 354–365. <https://doi.org/10.1016/j.xkme.2019.07.014>
- Sung, C., Hershberger, P.E., Lockwood, M.B. (2023). Sickness symptoms in kidney transplant recipients: A scoping review. *Western Journal of Nursing Research* 45 (4): 344–362. <https://doi.org/10.1177/01939459221128125>
- Tannor, E.K., Bieber, B., Shah, D.S., et al. (2021). COVID-19 pandemic highlights global inequities in chronic hemodialysis care: A DOPPS/ISN survey. *Journal of the American Society of Nephrology* 32: 87–88. <https://pesquisa.bvsalud.org/global-literature-on-novel-coronavirus-2019-ncov/resource/pt/covidwho-1490194>
- Tannor, E.K., Bajpai, D., Nlandu, Y.M., et al. (2022). COVID-19 and kidney disease: progress in health inequity from low-income settings. *Seminars in Nephrology* 42 (5): 151318. <https://doi.org/10.1016/j.semnephrol.2023.151318>

- Taylor, D.M., Fraser, S.D.S., Bradley, J.A., et al. (2017). A systematic review of the prevalence and associations of limited health literacy in CKD. *Clinical Journal of the American Society of Nephrology* 12 (7): 1070–1084. <https://doi.org/10.2215/CJN.12921216>
- Tommel, J., Evers, A.W.M., van Hamersvelt, H.W., et al. (2021). Predicting health-related quality of life in dialysis patients: Factors related to negative outcome expectancies and social support. *Patient Education and Counselling* 104 (6): 1474–1480. <https://doi.org/10.1016/j.pec.2020.11.019>
- Tong, A., Manns, B., Wang, A.Y.M. et al. (2018). Implementing core outcomes in kidney disease: report of the standardized outcomes in nephrology (SONG) implementation workshop. *Kidney International* 94 (6): 1053–1068. <https://doi.org/10.1016/j.kint.2018.08.018>
- Tong, A., Levey, A.S., Eckardt, K-U, et al. (2020). Patient and caregiver perspectives on terms used to describe kidney health. *Clinical Journal of the American Society of Nephrology* 15 (7): 937–948. <https://doi.org/10.2215/CJN.00900120>
- Tong, A., Oberbauer, R., Bellini, M.I., et al. (2022). Patient reported outcomes as endpoints in clinical trials of kidney transplantation interventions. *Transplant International* 35: 10134. <https://doi.org/10.3389/ti.2022.10134>
- Toth-Manikowski, S.M., Hsu, J.Y., Fischer, M.J., et al. (2022). Chronic renal insufficiency cohort (CRIC) study investigators. Emergency department/urgent care as usual source of care and clinical outcomes in CKD: Findings from the chronic renal insufficiency cohort study. *Kidney Medicine* 4 (4): 100424. <https://doi.org/10.1016/j.xkme.2022.100424>
- Turpin, A. (2018). Treatment of a patient with psychotic disorder undergoing haemodialysis: a case report. *Psychiatry Danubina* 30 (4): 169–171
- Treadwell, A. (2017) Examining depression in patients. *Nephrology Nursing Journal* 44 (4): 295–307.
- Vaishnav, B.S., Hirapara, J.J., Shah, M.K. (2022). Study of effect of guided meditation on quality of life in patients of end stage renal disease (ESRD) on maintenance hemodialysis – a randomised controlled trial. *BMC Complementary Medicine and Therapies* 22 (1): 238. <https://doi.org/10.1186/s12906-022-03717-8>
- Van Alphen, A., Bosch, T., Kupka, R., et al. (2021). Chronic kidney disease in lithium-treated patients, incidence, and rate of decline. *International Journal of Bipolar Disorders* 9 (1). <https://doi.org/10.1186/s40345-020-00204-2>
- Vanholder, R., Annemans, L., Bello, A.K., et al. (2021). Fighting the unbearable lightness of neglecting kidney health: the decade of the kidney. *Clinical Kidney Journal* 14 (7): 1719–1730. <https://doi.org/10.1093/ckj/sfab070>
- Vanholder, R., Paul, T., Conway, P.T., Gallego, D. et al. (2022). The European Kidney Health Alliance (EKHA) and the Decade of the Kidney™. *Nephrology Dialysis Transplantation*. <https://doi.org/10.1093/ndt/gfac211>
- Whitney, D., Schmidt, M., Bell, S., et al. (2020). Incidence rate of advanced chronic kidney disease among privately insured adults with neurodevelopmental disabilities. *Clinical Epidemiology* 12: 235–243. <https://doi.org/10.2147/clep.s242264>
- Wiles, K., Chappell, L., Clarke, K., et al. (2019). *UK Kidney Association Clinical Practice Guideline. Pregnancy and Renal Disease*. <https://ukkidney.org/sites/renal.org/files/FINAL-Pregnancy-Guideline-September-2019.pdf> (accessed 3 April 2023)
- Wilk A, Hu J, Chehal P, et al. (2022). National estimates of mental health needs among adults with self-reported chronic kidney disease in the United States. *Kidney International Reports*. <https://doi.org/10.1016/j.ekir.2022.04.088>
- Wilkie, M., Barnes, T. (2019). Shared hemodialysis care: increasing patient involvement in center-based dialysis. *CJASN* 14 (9): 1402–1404. <https://doi.org/10.2215/CJN.02050219>
- Williams, L.A., Graff, J.C., Wicks, M.N., et al. (2017). Male caregivers of persons with end stage renal disease: A qualitative study. *Nephrology Nursing Journal* 44 (3): 234–243
- Wilson, A., Carswell, C., Noble, H. (2021). Developing guidance on implementing volunteer-led intradialytic arts activities in haemodialysis units. *Healthcare* 9: 1506. <https://doi.org/10.3390/healthcare9111>
- Wilson, A., McKeaveney, C., Carswell, C., et al. (2022). Examining the acceptability and feasibility of the compassionate mindful resilience (CMR) programme in adult patients with chronic kidney disease: The COSMIC study protocol. *Healthcare* 10 (8): 1387. <https://doi.org/10.3390/healthcare10081387>
- Winterbottom, A.E., Mooney, A., Russon, L., et al. (2020). Kidney disease pathways, options, and decisions: an environmental scan of international patient decision aids. *Nephrology Dialysis Transplantation* 35 (12): 2072–2082. <https://doi.org/10.1093/ndt/gfaa102>
- Woo, K., Fuld, R., Grandinetti, A., et al. (2022). Patient-reported outcomes in hemodialysis vascular access: A call to action. *Journal of Vascular Access* 23 (6): 973–980. <https://doi.org/10.1177/11297298211018295>
- Woodrow, G., Fan, S.L., Reid, C., et al. (2017). Renal Association Clinical Practice Guideline on peritoneal dialysis in adults and children. *BMC Nephrology* 18: 33. <https://doi.org/10.1186/s12882-017-0687-2>
- Wu, H.H.L., Dhaygude, A.P., Mitra, S., et al. (2022). Home dialysis in older adults: challenges and solutions. *Clinical Kidney Journal* 16 (3): 422–431. <https://doi.org/10.1093/ckj/sfac2204>
- Wu, X.L., Ji, B., Yao, S.D., et al. (2021). Effect of music intervention during hemodialysis: a comprehensive meta-analysis. *European Review for Medical and Pharmacological Sciences* 25 (10): 3822–3834. https://doi.org/10.26355/eurrev_202105_25950

Yangöz, Ş.T., Özer, Z. (2022). Effects of music intervention on physical and psychological problems in adults receiving haemodialysis treatment: A systematic review and meta-analysis. *Journal of Clinical Nursing* 31 (23–24): 3305–3326. <https://doi.org/10.1111/jocn.16199>

Zhang, C., Mu, H., Yang, Y.F., et al. (2023). Effect of aromatherapy on quality of life in maintenance hemodialysis patients: a systematic

review and meta-analysis. *Renal Failure* 45 (1): 2164202. <https://doi.org/10.1080/0886022X.2022.2164202>

Zisman-Ilani, Y. (2022). The mental health crisis of individuals with intellectual and developmental disabilities. *Psychological Services* 73 (3): 245–246. <https://doi.org/10.1176/appi.ps.202200022>

Acute Kidney Injury

Marissa Dainton

Canterbury Christ Church University, Canterbury, UK

CHAPTER 5

LEARNING OUTCOMES

- to understand the different types and causes of acute kidney injury (AKI).
- to help and support the patient and family during an episode of AKI.
- to describe the signs and symptoms of AKI.
- to analyse the management of those with AKI.
- to evaluate the various treatment options for AKI.

INTRODUCTION

Acute kidney injury (AKI) results when there is an abrupt and rapid loss of kidney function which results in the retention of nitrogenous waste products (Jha 2016). AKI is associated with significantly increased mortality risk, and patients who recover are at increased risk of developing chronic kidney disease (CKD). In 2018, the UK Renal Registry (UKRR) identified just over 1.5 million AKI alerts in UK hospitals impacting around 500,000 people. Two-thirds of AKI episodes were recorded in adults of 65 years or older. AKI rates are highest in people admitted to hospital as emergencies, with about 70 AKI episodes per 1000 emergency admissions; the figure is nearer 5 per 1000 for elective admissions. Over 7 in 10 AKI cases resulted in a hospital stay, with about 40% of those resulting from community acquired AKI and about a third developing AKI whilst in hospital. Nearly 20% of patients for whom there was an AKI alert died within 30 days of the first alert (UKRR 2020).

Previous studies have concluded that 30% of AKI cases that occur during hospital admission are avoidable, and only around half of patients with AKI were deemed to have received care that was regarded as good (NCEPOD 2009). Costs to the National Health Service (NHS) of AKI have been estimated to be between £434 million and £620 million per year, exceeding the combined costs from breast, lung, and skin cancers (NICE 2019).

In addition, the COVID-19 pandemic saw increased rates of AKI among patients with severe symptoms of COVID-19. A study of nearly 4000 patients hospitalised with COVID-19 recorded AKI in 46% of the patients, with

19% of those requiring kidney replacement therapy (Chan et al. 2021).

In 2009, poor recognition of patients at risk of developing AKI, and/or suboptimal care in the early stages of AKI, was identified as significantly contributing to AKI prevalence within acute care (NCEPOD 2009). This was important because the study demonstrated that the prognosis for patients experiencing AKI could be significantly improved with effective early treatment, especially with respect to reduced risk of mortality and reduced risk of developing CKD. In response to this, the National Institute for Health and Care Excellence (NICE) developed a guideline for AKI detection and management in 2013, which was subsequently updated in 2023 (NICE 2023).

AKI can be seen as a spectrum of injury from impairment to failure, which may result in the need for kidney replacement therapy (KRT). Clinically, AKI is characterised by a rapid reduction in kidney function resulting in dysregulation of extracellular fluid volume, electrolytes, and acid–base balance (Jha 2016). Depending on its severity and duration, AKI is often transient in nature and, with appropriate nursing care, the patient can regain normal kidney function. However, without effective specialised treatment, the patient may be denied the opportunity to make a full recovery and potentially go on to develop CKD and end-stage kidney disease (ESKD).

The aim of this chapter is to emphasise the vital role the nurse plays in the prevention of progression to AKI, progression of AKI through the stages, and of the delivery of care for the patient in AKI. The nurse is vital to the

well-being of the patient as the nurse monitors the patient for complications, participates in KRT, assesses the patient's progress and response to treatment, and provides physical and emotional support. In this central role, the nurse can maintain close links with the patient's family, which can be instrumental to a family-centred approach to the patient's treatment. The alliance between the patient, the family, and the nurse is paramount in keeping the family informed of the patient's condition, assisting them to understand treatments, and providing psychological support.

SIGNS AND SYMPTOMS OF AKI

Due to the severity of symptoms involved, most patients with advanced AKI (stages 4 and 5) are nursed in intensive care during the most severe phase to enable continuous kidney replacement therapy (CKRT). Specific nursing activities for CKRT are beyond the scope of this book, but further reading can be found at the end of this chapter regarding the options available for KRT. Kidney nurses are likely to be involved in recognising patients at risk of

developing AKI, its onset, and in ongoing care for patients who may remain dependent on KRT and other specialist interventions after the most acute phase.

Figure 5.1 gives an overview of the signs and symptoms of AKI.

MORTALITY FOLLOWING AKI

There are a number of patient groups for which AKI has a particularly high mortality rate. For example, AKI occurs in around 40% of patients with severe sepsis and septic shock, and patients in this group are at greatly increased risk of mortality, ranging from 42% of patients in stage 1 AKI to as high as 85% in stage 3 AKI (Umbro et al. 2016). Early identification of the symptoms of AKI and rapid intervention with appropriate and evidence-based therapy is identified as essential in promoting maximal patient recovery and minimising long-term negative complications (NICE 2023). The nurse must therefore play a major role in assisting physicians and other members of the multidisciplinary team in optimising the treatment for this highly vulnerable group of

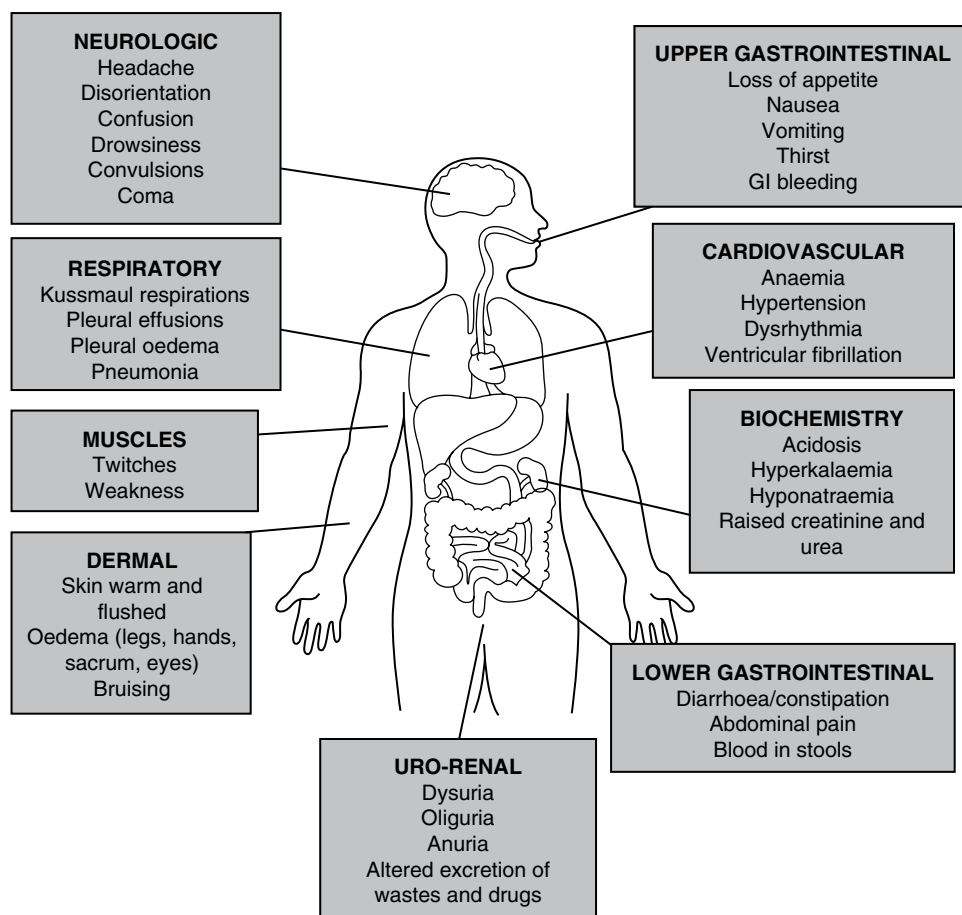


FIGURE 5.1 AKI – selected symptoms (O'Callaghan et al. 2004 / John Wiley & Sons).

patients. The development of new biochemical markers may enable a diagnosis to be made before changes are seen in either serum creatinine (SCr) or the urine output (UO).

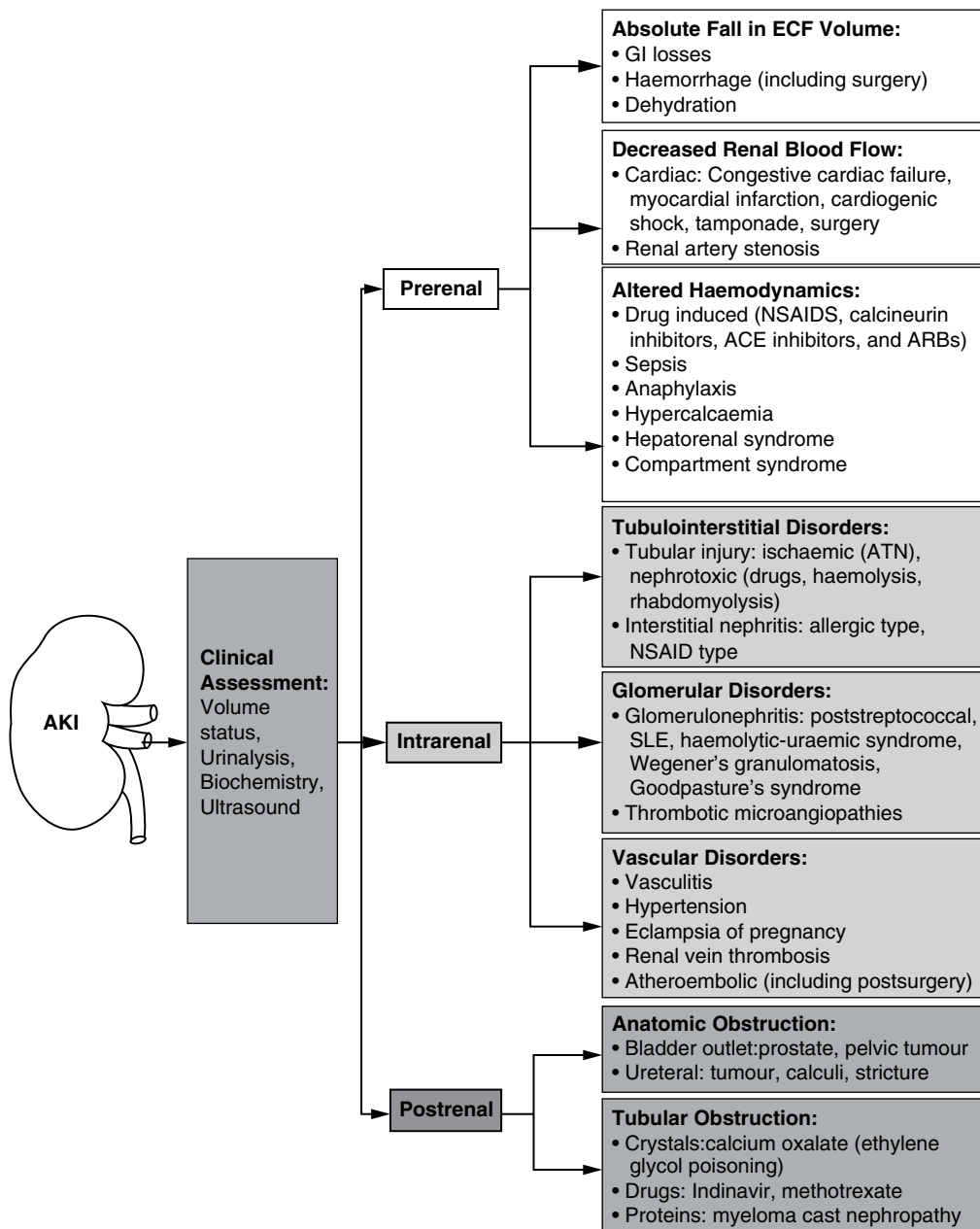
It is important for nurses, patients, and carers to be able to understand that AKI is a serious condition that should never be underestimated. Constant improvements in dialysis technology, combined with a growing CKD population and limited funds, have put clinicians under pressure to try and predict the outcomes of treatment.

CLASSIFICATION OF ACUTE KIDNEY INJURY

AKI may be divided into three major categories, in which each category has a physiological location of the insult (Table 5.1):

- *Pre-renal*. This relates to the ineffective perfusion of kidneys which are structurally normal.
- *Renal (intrinsic)*. Damage is to the renal parenchyma, sometimes secondary to pre-renal problems.

Table 5.1 Acute kidney injury (AKI): major causes and aetiology (Rennke and Denker 2014 / Wolters Kluwer Health).



- *Post-renal*. Disordered urinary drainage occurs from one or both kidneys or a single functioning kidney.

An acute impairment may also present in a patient with existing CKD, which may lead to further structural damage; this presentation is often referred to as acute-on-chronic kidney disease and evidence would indicate that this is an increasing group (Jha 2016).

PRE-RENAL FAILURE

Pre-renal causes of AKI are directly related to hypoperfusion states or a decline in the blood supply to the kidneys. Since the kidneys receive higher blood flow per unit mass than any other organ in the body, due to the complex

capillary structure in the nephrons, they are especially sensitive to hypoperfusion. In pre-renal failure, the structure of the kidneys remains normal; however, when the renal blood supply is restricted, glomerular filtration is reduced, causing decreased perfusion of the kidneys. The net effect is a decreased blood flow to the glomeruli and the nephrons, which leads to ineffective filtration and disordered secretion and reabsorption through the nephron because of inadequate blood flow. Without an effective renal plasma flow rate, the glomeruli are unable to filter waste from the blood even if the structure of the renal tubules remains intact (Figure 5.2).

In this pre-renal state, urine osmolarity is high and sodium low, which is consistent with renal hypoperfusion and well-preserved renal function. If, at this stage, renal

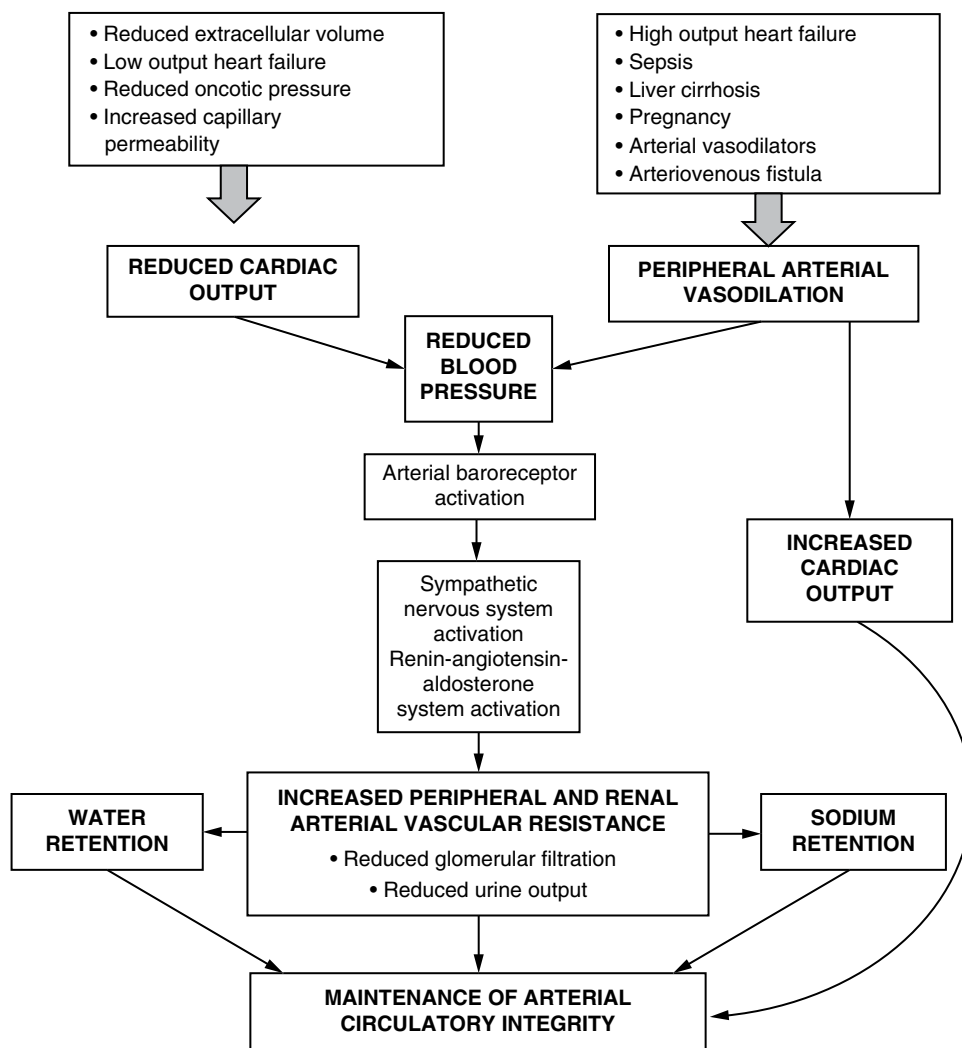


FIGURE 5.2 Pre-renal failure progression (Steddon et al. 2014 / Oxford University Press).

blood flow can be quickly restored, then normal renal function will usually return. However, if the pre-renal state is prolonged, then this may lead to ischaemic damage, particularly within the nephrons, due to poor perfusion, which in turn may lead to acute tubular necrosis (ATN) (Pakula and Skinner 2016).

It is estimated that around 30% of cases of AKI which occur during hospital admission are both predictable and avoidable (Kerr et al. 2014). Early recognition, diagnosis, and treatment are vital in cases of pre-renal disease, in order to prevent the condition progressing to end-stage kidney disease with a degree of parenchymal damage. Nurses can play a large role in the recognition and management of this group of patients.

Cardiorenal Syndrome

Cardiorenal syndrome (CRS) covers a range of conditions whereby acute or chronic dysfunction in either the heart or the kidneys precipitate acute or chronic dysfunction in the other organ. This could involve pre-renal causes of AKI related to a heart failure induced reduction in effective blood supply to the renal tubules. In the early stages of CRS diuretic treatment can be effective through reducing fluid retention and consequent congestive cardiac failure, but as AKI develops, diuretic treatments will cease to be effective and ultrafiltration will be required. Pharmacological therapy includes the use of vasodilators, inotropes, ACE-inhibitors, and ARBs. More recently DPP-4 inhibitors, and, especially in diabetic patients, SGLT-2 inhibitors and have also been found to be effective (Rangaswami et al. 2019). Once AKI develops in CRS a vicious circle can be induced whereby the AKI induces and/or perpetuates further cardiac pathologies, such as arrhythmias. In-hospital mortality in CRS can exceed 45%, though more recent research has indicated a rate nearer 25% (Drubel et al. 2022). Effective treatment of CRS is enhanced by effective interprofessional collaboration between kidney and cardiology care teams, and diabetic care teams in cases where diabetes is a further complication.

For further reading on CRS refer to Rangaswami et al. 2019.

RENAL (INTRINSIC) FAILURE

This cause is sometimes referred to as intrinsic or intrarenal failure and is associated with structural damage to the glomeruli and renal tubules. The difference between pre- and post-renal failure and intrinsic failure is that in intrinsic failure, the correction of the aetiology will not guarantee the complete recovery of renal function, because of damage to the nephron itself. Here the episode of AKI may have a lengthy duration and can often lead to CKD.

The clinical course of intrinsic renal failure is often complex and, depending on underlying disorders, the recovery may be prolonged for up to 6 weeks. As illustrated in Table 5.1, there are a wide variety of causes for intrinsic renal failure, which may involve multisystem disease or originate from a primary kidney disorder, but often involve complicating severe illness that causes vasomotor nephropathy. Some specific causes are now discussed.

Acute interstitial nephritis

This condition often follows exposure to drugs in the form of antibiotics, analgesics, and nonsteroidal anti-inflammatory agents. Infections can cause a very similar clinical and pathological picture, and these include *Salmonella*, *Streptococcus*, *Meningococcus*, leptospirosis, and many viral disorders.

Other categories of interstitial nephritis are caused by systemic disease, such as systemic lupus erythematosus or sarcoidosis.

Clinical features Fever, rash, arthralgia, back pain, and eosinophilia are clinical features of acute interstitial nephritis. AKI may not develop for some weeks but in some cases kidney dysfunction may occur within a few hours after exposure to a causative drug.

Rhabdomyolysis

Rhabdomyolysis is a result of the release of muscle contents, including myoglobin, into the plasma. Causes include crush injury, prolonged immobility, compartment syndrome, sickle cell disease, excessive exertion, shock, electrocution, status epilepticus, and intravenous drug abuse. These causes damage muscle tissue, allowing the pigment myoglobin to be released into the plasma. Myoglobin is an iron- and oxygen-binding protein and is only found in the bloodstream after muscle injury. At high plasma levels it becomes nephrotoxic. If treated early, it can be successfully cured with fluid resuscitation, but failure to respond quickly can lead to permanent damage to both kidney tissue and the site of the trauma (Steddon et al. 2014).

Clinical features The urine is often brown or coffee-coloured due to the presence of myoglobin. Patients often present with acute illness, with fever, weakness, pain, nausea, and vomiting.

Kidney failure and liver disease

AKI is often associated with acute liver injury that may result from:

- paracetamol overdose;
- circulatory shock;
- severe leptospirosis sepsis.

It may also be seen in surgery on the biliary tract.

For the patient with advanced liver disease, the onset of kidney injury is often referred to as hepato-renal syndrome (HRS). This occurs in advanced liver dysfunction in conjunction with ascites and portal hypertension. Common causes of HRS include hypovolaemia, sepsis, nephrotoxic agents, and glomerulonephritis. Successful management relies on early recognition of risk factors such as existing cirrhosis and ascites, over diuresis, GI bleeding, sepsis, and major surgery. These patients often require intensive care and multi-system support. KRT is seen only as a bridge to potential liver transplantation (Steddon et al. 2014).

Cortical necrosis

Cortical necrosis may follow any course of intensive or prolonged ischaemia. The condition is also associated with sepsis, shock, transfusion reactions, and burns.

Kidney biopsy reveals pathology of patchy necrosis of the glomeruli, tubules, and small vessels of the renal cortex. The renal medulla remains intact but the renal cortex becomes infarcted and calcifies, and this may be seen on plain abdominal X-ray.

The return of renal function is often slow but, if cortical necrosis is extensive, recovery is unlikely and the patient may become dialysis dependent.

Acute tubular necrosis (ATN)

AKI due to ischaemic changes or toxic kidney injury presents a clinical syndrome that is often referred to as ATN. It is a very common cause of AKI and has a high mortality rate of around 50%. It causes damage to the tubular portion of the nephron. Many years of improvements in dialysis technologies and other aspects of kidney care have until recently done little to improve the prognosis for patients with ATN. Recent work has focused on the development of novel markers for prediction of renal recovery and it is thought that serum cystatin C may prove a better predictor than the traditionally used SCr (Gharaibeh et al. 2018).

Although the aetiology of ATN can vary, the common factor is that there is a reduction of oxygen and nutrients to the active tubular cells, which results in a lack of cell function and patchy necrosis. The tubular cells will regenerate at the basement membrane level. Treatment focus, in the absence of effective novel approaches, remains supportive care with dialysis allied with correction of electrolyte and metabolic disturbances (Rennke and Denker 2014).

Ischaemic ATN is also associated with inadequate perfusion to the kidney, in that the efferent and afferent arterioles are unable to maintain their autoregulatory

function, and this leads to a fall in the glomerular filtration rate. This interruption in blood flow to the kidney may also be due to surgical intervention, for example aortic repair.

Nephrotoxicity

In any patient with AKI, particularly ATN, a potential causative effect could be a therapeutic agent. Therapeutic agents can affect the kidney in any of the three categories listed, as illustrated in Table 5.2 (Perezella 2009, Steddon et al. 2014).

Contrast-induced acute kidney injury (CI-AKI) occurs within 72 hours of the patient receiving the contrast media. AKI results from a combination of afferent arteriolar vasoconstriction and direct toxicity of the contrast media to the tubule epithelial cells. Before offering iodine-based contrast media to adults, it is important to assess their risk of AKI but emergency imaging should not be delayed. Increased risk of AKI is associated with:

- Chronic kidney disease. Adults with an eGFR less than 40 ml/min/1.73 m² are at particular risk.
- Diabetes, but only with chronic kidney disease. Adults with an eGFR less than 40 ml/min/1.73 m² are at particular risk.
- Heart failure.
- Kidney transplant.
- Age. People age 75 years or over are at increased risk.
- Hypovolaemia.

For adults needing non-emergency imaging who are assessed as being at increased risk of kidney injury, it is

Table 5.2 Effects of therapeutic agents on the kidney.

Clinical syndrome	Causative agents
Pre-renal	Ciclosporin, radiocontrast, amphotericin B, ACE inhibitors, NSAIDs
Intrinsic: acute tubular necrosis (ATN)	Aminoglycosides, amphotericin B, cephalosporins
Acute interstitial nephritis	Penicillins, cephalosporins, sulphonamides, rifampicin, NSAIDs, interferon, interleukin-2
Rhabdomyolysis	Amphetamines, statins, antimalarials, opiate abuse
Post-renal	Aciclovir, analgesic abuse
	Other heavy metals, including gold, lithium, mercury, silver
ACE, angiotensin-converting enzyme; NSAIDs, nonsteroidal anti-inflammatory drugs.	

important to investigate for chronic kidney disease before offering iodine-based contrast media. Measure eGFR or check an eGFR result obtained within the past 3 months (NICE 2019, amended 2023).

Oral hydration should be encouraged before and after procedures using intravenous iodine-based contrast media in adults at increased risk of contrast-induced acute kidney injury. For inpatients having iodine-based contrast media, consider intravenous volume expansion with either isotonic sodium bicarbonate or 0.9% sodium chloride if they are at particularly high risk.

COVID-19 and AKI

Exploration into the underlying pathophysiology of AKI in cases of severe infection with the SARS-CoV-2 (COVID-19) virus is ongoing. However, there is growing evidence that suggests the cause is related to infective damage to the renal vascular endothelium. Particles of the SARS-CoV-2 virus have been detected in renal endothelial cells, which it is suggested indicates intracellular proliferation of the virus being directly related to the development of intrinsic AKI. It is also postulated that the virus may infect the podocytes in the renal tubular epithelium leading to ATN and protein leakage (Fortin et al. 2021). Additionally, patients experiencing severe COVID-19 infection and requiring support in a critical care environment are vulnerable to other causes of AKI associated with severe disease, including hypovolaemia, cardiorenal syndrome and rhabdomyolysis.

POST-RENAL FAILURE

Post-renal conditions obstruct the flow of urine, so the obstruction has to be bilateral or located within the bladder or urethra in order to cause failure. The rapidity of recovery will depend on the duration and completeness of the obstruction. The urinary tract may be obstructed by three mechanisms:

- *Intraluminal* (obstruction from within) – calculi, blood clots, renal papilla.
- *Intramural* (disease of the wall) – transitional cell cancer, fibrosis, inflammation, infection.
- *Extrinsic* (obstruction from outside) – trauma, prostatic hypertrophy, abdominal tumour, inflammation, fibrosis, haemorrhage.

The consequences in terms of progression to AKI include reduced GFR, reduced renal blood flow (following an initial rise), impaired renal concentrating ability, and impaired distal tubular function.

As with all types of kidney injury, it is important to find the cause and start treatment as soon as possible since, in theory, all post-renal failure is reversible. The initial recovery stage is usually characterised by a marked post-obstructive diuresis (Field et al. 2010).

AKI CLASSIFICATION SYSTEMS

The Acute Dialysis Quality Initiative (ADQI), in 2004, proposed the introduction of a diagnostic criterion for AKI using SCr levels and UO volumes over standardised periods of time. The system was called RIFLE (Table 5.3) (Ricci et al. 2007). The system provided a uniform standard for diagnosis and classification of AKI to optimise the treatment of patients with kidney disease. Many of the ADQI group later collaborated to become the Acute Kidney Injury Network (AKIN), which modified RIFLE with regards the creatinine measure, due to the clinical significance of relatively small rises in SCr. As a result, the AKIN group modified RIFLE to the new AKI staging system, AKIN (Table 5.4), which reflects these smaller changes, with the AKIN corresponding to the earlier RIFLE stages. Stage 1 relates to risk, while AKIN stage 2 relates to injury,

Table 5.3 RIFLE classification of AKI.

Category	GFR criteria	Urine output (UO)
Risk	Increase in creatinine $\times$ 1.5 or GFR $\geq$ 25%	UO $<$ 0.5 ml kg^{-1} h^{-1} $\times$ 6 h
Injury	Increase in creatinine $\times$ 2 or eGFR $\geq$ 50%	UO $<$ 0.5 ml kg^{-1} h^{-1} $\times$ 12 h
Failure	Increase in creatinine $\times$ 3 or GFR $\geq$ 75%	UO $<$ 0.3 ml kg^{-1} h^{-1} $\times$ 24 h or anuria $\times$ 12 h
Loss	Complete loss of kidney function $\geq$ 4 weeks	
ESKD	End-stage kidney disease ($\geq$ 3 months)	

Table 5.4 AKIN classification of AKI.

Category	Serum creatinine (SCr)	Urine output (UO)
Stage 1	SCr $\geq$ 150–200% from baseline	$<$ 0.5 ml kg^{-1} h^{-1} for $>$ 6 h
Stage 2	SCr $\geq$ 200–300% from baseline	$<$ 0.5 ml kg^{-1} h^{-1} for $>$ 6 h
Stage 3	SCr $\geq$ 300% from baseline OR SCr $\geq$ 54 $\mu\text{mol l}^{-1}$ with an acute rise of at least 44 $\mu\text{mol l}^{-1}$ or commencement KRT	$<$ 0.3 ml kg^{-1} h^{-1} for $>$ 24 h or anuria for $>$ 12 h

Table 5.5 KDIGO classification of AKI. Recommended by the UK Kidney Association.

Category	Serum creatinine (SCr)	Urine output (UO)
Stage 1	> 1.5–1.9 × baseline or increase in SCr ≥ 0.3 mgdl ⁻¹ (≥26.5μmol l ⁻¹)	<0.5ml kg ⁻¹ h ⁻¹ for 6–12 h
Stage 2	>2–2.9 × baseline	<0.5ml kg ⁻¹ h ⁻¹ > 12h
Stage 3	3 × baseline or increase in SCr ≥ 4 mgdl ⁻¹ (≥ 353.6μmol l ⁻¹) or initiation of KRT	<0.3ml kg ⁻¹ h ⁻¹ for ≥ 24 h or anuria for ≥ 12 h

and AKIN stage 3 corresponds to failure. The ‘loss’ and ‘end-stage kidney disease’ categories were dropped from the staging system but remain outcomes. The AKIN classification also introduced a baseline measure and dropped the use of eGFR as this is not an accurate measure of kidney function in AKI.

The NICE (2023) clinical guideline now recommends detecting AKI, in line with the (p)RIFLE (paediatric Risk, Injury, Failure, Loss, End stage renal disease), AKIN (Acute Kidney Injury Network) or KDIGO (Kidney Disease: Improving Global Outcomes) definitions (Table 5.5), by using any of the following criteria:

- SCr has risen by 26 μmol l⁻¹ or more within 48 hours.
- SCr has risen 50% or more within the past 7 days.
- UO has fallen to less than 0.5 ml kg⁻¹ h⁻¹ for more than 6 hours in adults and more than 8 hours in children and adolescents.
- eGFR has fallen 25% or more in children and young people within the last 7 days.

IDENTIFYING THE CAUSE(S) OF ACUTE KIDNEY INJURY

NICE (2023) recommends the following diagnostic procedures to identify the possible cause(s) of AKI.

URINALYSIS

NICE (2023) recommends performing urine dipstick testing for blood, protein, leucocytes, nitrites, and glucose in any patient in whom AKI is suspected as soon as possible. Diagnosis of acute nephritis should be considered, and the patient referred to a nephrologist when a urine dipstick shows signs of haematuria and proteinuria in the absence

of urinary tract infection or trauma, even if there is no obvious cause of AKI.

ULTRASOUND

NICE (2023) does not recommend routine use of ultrasonography of the urinary tract once the cause of AKI has been established. However, in cases where pyonephrosis (infected and obstructed kidneys) are suspected, ultrasonography of the urinary tract should be performed within 6 hours of initial assessment.

Management of Acute Kidney Injury

Since normal kidney function is essential to homeostasis of the body, particularly regarding volume, electrolyte balance, acid–base balance, and excretion of nitrogenous waste products, loss of these functions can lead to hyperkalaemia, volume overload, acidosis, and uraemia.

Prevention is better than cure, so early detection and treatment of AKI will prevent rapid deterioration. Failure to identify deterioration in acutely unwell patients has been identified as a factor in many of the cases of hospital-acquired AKI. NICE (2023) recommends the use of early warning scoring systems such as the National Early Warning Score (NEWS) (RCP 2017) in order to improve the rate of early detection of patients at risk of developing AKI. Some people are at a greater risk of AKI – these include patients who have CKD, cardiac failure, liver disease, and diabetes, and those who are over 60 years of age. The clinical management goals for patients with AKI can be divided into three main categories:

- restoration of renal perfusion;
- minimising toxic effects;
- correction of metabolic derangements.

Relieve urological obstruction

All patients with upper tract urological obstruction should be referred to a urologist. Referral should be immediate in the presence of any of the following symptoms: pyelonephrosis, obstructed solitary kidney, bilateral upper urinary tract obstruction, or complications of AKI caused by urological obstruction. Nephrostomy or stenting, if required to relieve the obstruction, should happen within 12 hours of initial diagnosis (NICE 2023).

Hyperkalaemia

Hyperkalaemia is an often-fatal complication in AKI. The failing kidney is unable to excrete potassium effectively when the patient is oliguric (<400 ml urine day) or anuric (no

urine). It is further complicated by the very complex treatment of an individual who is often septic, hypoxic, and requiring blood transfusions and potassium-containing drugs.

KRT is the most efficient treatment for hyperkalaemia, but this may take time to effect if vascular access is required. Other alternatives are available, but these are generally temporary solutions only, as they facilitate movement of potassium from the vascular compartment rather than removal:

- The administration of intravenous insulin and dextrose or nebulised salbutamol will help move potassium ions back into the intracellular compartment and away from the extracellular compartment. It is important to monitor the patient's blood sugar as hypo- or hyperglycaemia can occur. Also, it is important to measure the heart rate, which can increase in response to salbutamol.
- Calcium gluconate is recommended in most cases to reduce the cardiotoxicity and decrease the cardiac membrane excitability.
- Oral or rectal potassium exchange agents in the form of calcium resonium (which is a slower-acting treatment, often used as maintenance treatment for hyperkalaemia).

Volume overload

Successful volume homeostasis permits maintenance of a constant internal circulatory and extracellular volume despite consumption of varying quantities of water and salt intake and variable invisible losses of water.

The presence of oedema may be seen in the feet, legs, sacral area, and sometimes head and neck; as oedema follows gravity the location will depend largely on the positioning of the patient. The oedema is generally pitting in nature. The skin is particularly at risk at this stage and extra care must be taken. Shortness of breath and especially orthopnoea are indicative of pulmonary oedema.

Each patient in AKI should have an individual prescription for fluid and sodium intake. As a generalisation, the fluid intake volume should equal the daily UO plus 300–500 ml. Patients with a large insensible loss, such as happens with burns, obviously need a larger fluid intake and special care should be taken. It is important that the patient and family are involved in recording an accurate fluid balance, as failure to maintain accurate fluid balance records has often been implicated in poor patient management.

Pharmacological management of fluid overload should not routinely use diuretics, although loop diuretics might be used while the patient is awaiting KRT, or once kidney function is recovering (NICE 2023).

Metabolic acidosis

The presence of AKI must not lead the nurse to think that it is the only cause of acidosis until other causes have been eliminated, for example ketoacidosis and/or lactic acidosis.

Acidosis in kidney injury occurs when the renal tubules fail to regenerate bicarbonate and secrete hydrogen ions into the urine, which in turn causes an acid–base imbalance.

As most acid comes from the breakdown of dietary protein, it is possible to reduce the level of acidosis by limiting the level of protein intake. Another alternative is to infuse sodium bicarbonate, but care is needed to avoid fluid overload and hypernatraemia. The most efficient way of treating acute acidosis is via KRT.

Uraemia

The accumulation of nitrogenous waste products will produce acute uraemia. Symptoms of uraemia often include nausea, vomiting, hiccups, increasing bleeding, infection risks, neurological problems, irritability, confusion, and twitching. As previously mentioned, it is necessary to begin appropriate dialysis.

NUTRITIONAL ISSUES IN AKI

Patients with AKI are often very ill, and their metabolisms are often under great stress, resulting in the need for extra calories and extra protein (Fiaccadori et al. 2021). Protein calorie malnutrition is believed to be one of the leading factors in the high mortality rate seen in AKI. Key metabolic abnormalities associated with AKI include:

- protein catabolism;
- altered metabolism of amino acids;
- peripheral insulin resistance;
- reduced lipolysis and impaired fat clearance;
- dysfunction and depletion of antioxidant systems;
- pro-inflammatory state;
- immunodeficiency.

These changes result in negative nitrogen balance and depletion of body energy reserves. Protein catabolism is the major effect of AKI, especially in critical care environments, and the European Society for Clinical Nutrition and Metabolism (ESPEN) recommend that any hospitalised patient with AKI, especially if treated in a critical care environment for over 48 hours, should be screened for malnutrition using a generalised nutritional assessment tool.

Peripheral insulin resistance induces hyperglycaemia. Pro-inflammatory states impair immune competence, and plasma concentrations of water-soluble vitamins, and activation of vitamin D are both reduced.

Patients require an individualised nutritional assessment and feeding plan, which will require specialist input from a dietitian, taking into consideration their complex metabolic state, fluid balance, and current KRT. In the acutely ill patient, medical nutrition is considered to be the best treatment option by ESPEN whether the patient is receiving KRT or not. It is additionally recommended that any patient with AKI treated in an ICU for more than 48 hours should receive medical nutrition. The development of concentrated low-electrolyte feeds has proven invaluable in allowing delivery of optimal protein and calories with the minimum of fluid and electrolytes. Nutritional support has several aims:

- Prevent protein energy wasting.
- Preserve lean body mass and prevent or minimise malnutrition.
- Avoid further metabolic derangements.
- Stimulate immunocompetence.
- Repair tissue damage.
- Preserve organ function.
- Maintain biochemistry/fluid balance.
- Enhance recovery.

For non-critically ill patients receiving hospital treatment but who can take oral nutrition ESPEN recommend the use of oral nutritional supplements. For patients, whether acutely ill or not, who cannot achieve at least 70% of nutritional requirements through oral intake, it is recommended that nutrition be supplemented with enteral or parenteral nutrition.

Assessment of lean body mass, muscle mass, and function should be carried out, ideally using body composition measurements rather than anthropometric measurements, as this is far more effective at identifying early muscle loss. In patients able to participate, it is recommended that muscle strength be regularly assessed through hand-grip strength. The ESPEN guidance does not provide detailed protein requirements for nutritional support in AKI but rather recommend that this be kept under constant review and be determined by the progression of the patient's baseline illness. The guidelines do note that prolonged KRT can exert a further negative influence on protein balance and therefore recommend that nutritional

protein levels may need to be higher in such patients. ESPEN further warn against over-feeding on the basis that this can make it difficult to maintain an appropriate nitrogen balance. Full details of the ESPEN nutritional recommendations in the care of AKI can be found in Fiaccadori et al. (2021). Also see Chapter 12.

INFECTION AND SEPSIS

Infection is known to contribute to the high mortality of patients with AKI (Wang et al. 2012) due to an increased risk of developing infections such as pneumonia, urinary tract infections, and sepsis, due to the large numbers of invasive devices they may need *in situ*. To reduce some of these risks it is a priority to remove all unnecessary lines, and universal precautions and guidelines for maintaining asepsis should be adhered to at all times.

Acute viral infections including HIV and SARS-CoV-2 have been identified as having major effects upon mortality in cases of AKI, especially in less developed healthcare environments (Kahindo et al. 2022).

Sepsis is a systematic inflammatory response in the presence of infection and is associated with organ dysfunction, hypoperfusion, and hypotension. Symptoms include a body temperature in excess of 38 °C or below 36 °C, a rapid heart rate in excess of 90 beats per minute, hyperventilation in excess of 20 breaths per minute, and a white cell count in excess of 12 000 cells l⁻¹. Sepsis contributes up to 60% of AKI cases in intensive care units and is the most common contributory factor for AKI in such patients (van der Slikke et al. 2021). Sepsis can develop extremely quickly and is associated with a very high mortality rate, and sepsis-induced AKI is often a significant contributory factor. The very high mortality rate in sepsis-induced AKI is in part explained by incomplete understanding of the pathophysiology but recent research (van der Slikke et al. 2021) suggests that damage to mitochondrial DNA and reduced mitochondrial mass is a potential causative factor. Key to minimising mortality and potential progression to AKI and other systems failures is early identification and management. NICE (2017) has produced a clinical guideline for the management of sepsis.

CLINICAL COURSE OF ACUTE KIDNEY INJURY

The clinical course of AKI can be divided into four stages or phases:

1. initiating stage;
2. oliguric stage;

3. diuretic stage;
4. recovery stage.

Types of UO can be found in Table 5.6.

Table 5.6 Types of urine output.

Type of urine output	Volume of urine
Anuria	No urine output
Oliguria	<400 ml day ⁻¹
Nonoliguria	>400 ml day ⁻¹
Polyuria	Normal or high urine output

INITIATING STAGE

This occurs when the kidneys are injured and when diagnosis is made, and treatment established. It can last anything from hours to days. Accurate assessment and rapid intervention can be crucial at this stage to prevent progression to the latter stages. Key risk factors for development of AKI include existing CKD, liver cirrhosis, heart failure, diabetes, hypovolaemia, systemic infection, known use of nephrotoxic agents, symptoms or history of urological obstruction, falling early warning scores, advanced age, major surgery, and use of contrast media (NICE 2023).

OLIGURIC STAGE

This can last from 5 days to over 15 days. When AKI persists for weeks, endocrine problems, such as reduced erythropoietin production, are noticed. Functional renal changes occur, such as decreased tubular transport, reduced urine formation, and lowered glomerular filtration. Renal healing will begin to occur, with the basement membrane being replaced with fibrous scar tissue and the nephron clogged with inflammatory products. The patient is particularly susceptible to bleeding and infection during this stage.

DIURETIC STAGE

With continued healing the kidney begins to regain most of its lost function, but this depends on the severity of the initial injury. The signs and symptoms of the original condition begin to disappear. UO can begin to increase back to normal levels of up to 3 l⁻¹ day⁻¹. Often a key sign of this phase will be a period of polyuria as the functions of filtration associated with the glomerulus and proximal nephron often recover prior to the reabsorption functions of the distal nephron. For this reason, careful fluid monitoring is essential, and patients are likely to require fluid and electrolyte support.

RECOVERY STAGE

The recovery stage can last from several months to over a year. The basement membrane is restored to its previous structure; scar tissue will remain but is not clinically significant. The kidneys respond in a regulatory excretory function to the body's needs.

KIDNEY REPLACEMENT THERAPY (KRT) IN ACUTE KIDNEY INJURY

The purpose of KRT is to prevent morbidity and to support the kidney during its recovery phase. Adults, children and young people should be referred immediately for kidney replacement therapy if any of the following are not responding to medical management:

- hyperkalaemia;
- metabolic acidosis;
- symptoms or complications of uraemia (for example, pericarditis or encephalopathy);
- fluid overload;
- pulmonary oedema.

The decision to start kidney replacement therapy should be based on the condition of the adult, child, or young person as a whole and not on an isolated urea, creatinine or potassium value (NICE 2023).

There are a variety of treatment options available for AKI and the choice will depend on physician preference, nurse expertise, and availability of the appropriate equipment. The options fall broadly into two categories: intermittent treatments (acute haemodialysis [HD] and haemodiafiltration [HDF]) and CKRTs, of which there are three basic types: continuous haemofiltration (HF), continuous HD, and continuous HDF. Treatments performed continuously over long periods of time allow optimal values to be obtained for urea and fluid exchange control, and electrolyte and acid-base balance. Historically there was more emphasis on the use of peritoneal dialysis in AKI, and there is some current interest in reconsidering this as an option in certain circumstances.

ACUTE INTERMITTENT HAEMODIALYSIS

In acute HD, certain factors need to be considered; these include time on dialysis (usually a maximum of 2 hours for the first treatment), frequency (daily dialysis may be required), potassium concentration of dialysate (3 mmol l⁻¹ K⁺ dialysate may be necessary), a biocompatible dialyser, and good fluid balance control. For those patients who are

too haemodynamically unstable for conventional HD, other forms of KRT may be appropriate.

INTERMITTENT HAEMODIAFILTRATION

Intermittent HDF can be a therapy option for patients with AKI or ERF. It combines the advantages of diffusion (dialysis) with convection HF, and it is suitable for use in patients with cardiovascular instability, especially those with fluid overload. It has superior small solute clearance over HF. Blood flow rates are higher than those of continuous HDF and it requires an HDF membrane that is more permeable than a normal haemofilter. However, due to the efficiency of small molecule clearance, this would not be a treatment of choice for the patient with severe uraemia at risk of disequilibrium. The high blood flow rates associated with HDF require excellent vascular access and this can be an issue in patients being treated acutely.

CONTINUOUS KIDNEY REPLACEMENT THERAPY

The use of CKRT has developed enormously during recent years and involves either dialysis (solute removal using diffusion) or filtration (solute and water removal using convection)

or a combination of treatments. The advantage of continuous therapy is the slower rate of fluid or solute removal, thus making it better tolerated by critically ill patients.

The nurses in the intensive care unit have developed their skills, taking on this responsibility to ensure holistic care. It is recognised that intermittent HD may be contraindicated in patients with AKI who are critically ill. Complications such as cardiovascular instability, sepsis, and multiorgan failure make conventional intermittent treatments impractical.

CONTINUOUS HAEMOFILTRATION

Continuous HF provides solute removal by convection. It offers high-volume ultrafiltration using replacement fluid, which can be administered in a variety of concentrations according to the patient's biochemistry. The pump guarantees adequate blood flow to maintain required ultrafiltration rates. This method can be performed using several litres of replacement fluid each hour. This is dependent on the patient prescription, which is usually determined by their weight. The addition of a blood pump to the circuit removes the necessity for arterial access and provides a more reliable and controllable method of delivering treatment (Figure 5.3).

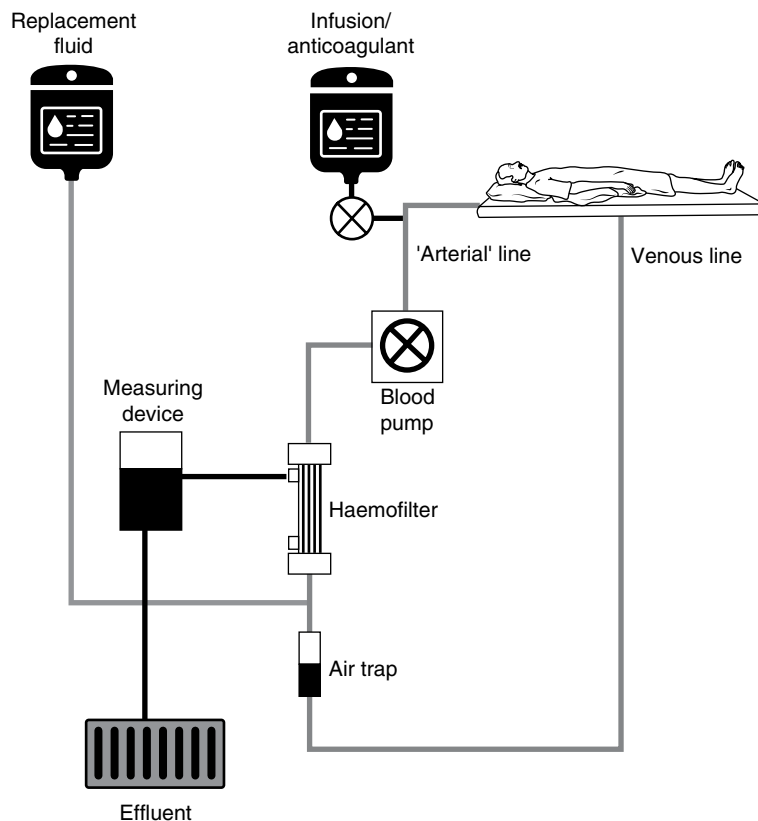


FIGURE 5.3 Continuous venovenous haemofiltration (HF).

CONTINUOUS HAEMODIAFILTRATION

To increase the efficiency of small-molecule clearance, a dialysis solution is continuously pumped through the filter in a countercurrent direction to the blood. Small molecule (urea) clearance by diffusion is more efficient. It is possible to use a standard blood monitor for the extracorporeal circuit and then use infusion pumps to administer dialysate and replacement fluid (Figure 5.4).

CONTINUOUS HAEMODIALYSIS

This method incorporates the same principles as intermittent HD but operates at a greatly reduced rate. From the nursing perspective, the use of fully automated systems provides a reliable and easy method of monitoring the fluid balance of patients who are critically ill.

The machine comprises a basic blood module with blood pump, venous and arterial pressure monitoring, and an air detector. The fluid monitor has two integral pumps: one to remove fluid from the filter and the second

to pump replacement fluid to the patient. The replacement fluid and the ultrafiltrate are suspended on a weigh scale, which calculates and controls a linear patient weight (Figure 5.5).

With such accurate fluid control, the nurse does not need to measure and record fluid loss and replacement constantly as with previous methods. The ultrafiltration rate and physiological solutions are prescribed by the physician based on available clinical data (fluid state, biochemistry).

ACUTE PERITONEAL DIALYSIS

There has been renewed interest in the potential for the use of peritoneal dialysis in the treatment of AKI in recent years, and it has remained a much-used treatment option in many less-developed health economies because of its greater technical simplicity and lower cost. For further reading please refer to the ISPD guidelines for peritoneal dialysis in acute kidney injury: 2020 update (adults) (Cullis et al. 2021).

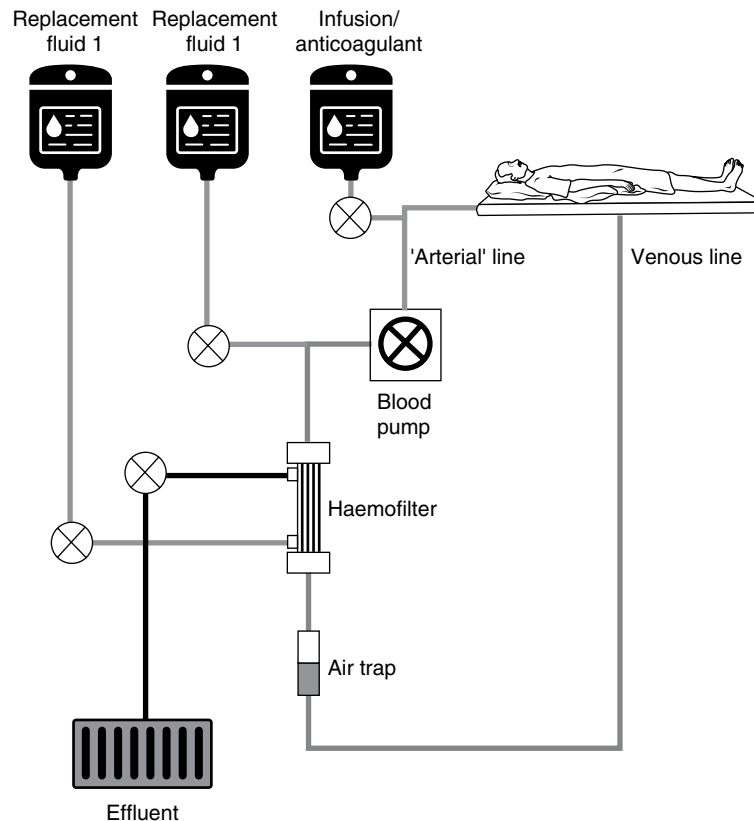


FIGURE 5.4 Continuous venovenous haemodiafiltration (HDF).

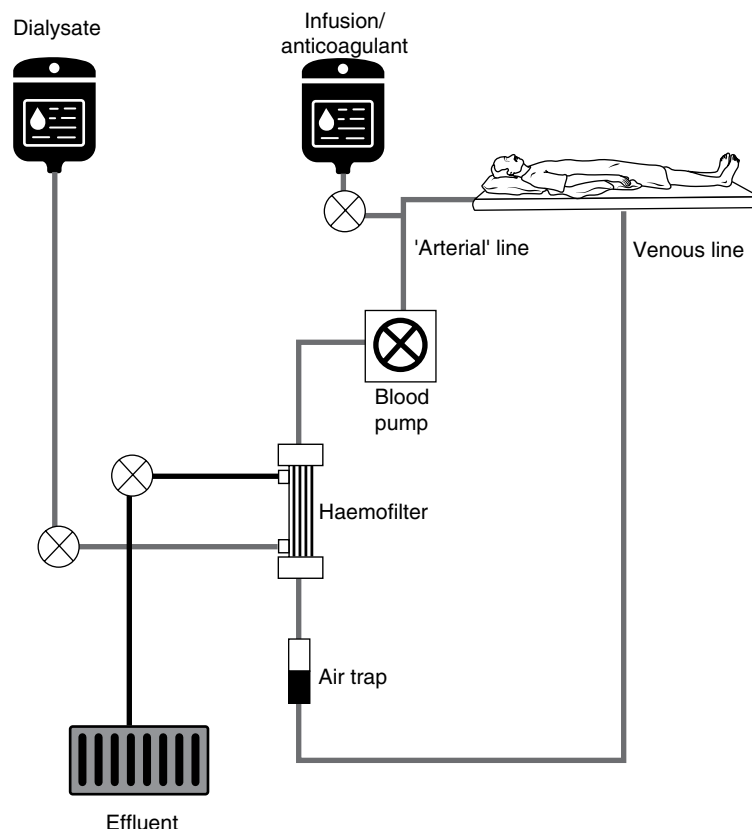


FIGURE 5.5 Continuous haemodialysis (HD).

PLASMA EXCHANGE

Therapeutic plasma exchange (TPE) is an extracorporeal blood purification technique, designed for the removal of large molecular-weight substances from the plasma (Seck et al. 2011) (Figure 5.6). Most TPE procedures are performed for neurological, immunological, or haematological diseases, including anti-GBM disease, thrombotic thrombocytopenic purpura (TTP), Guillain-Barré syndrome, systemic vasculitis, AKI secondary to myeloma of the kidney, and haemolytic uraemic syndrome (HUS).

Plasma is separated from whole blood and then a replacement fluid is infused in equal volumes to the plasma that has been removed. It is a nonspecific therapy, removing all circulating substances within the plasma. A plasma filter is used to separate the plasma from all other cellular elements, using a semi-permeable membrane. As TPE removes all circulating substances in the plasma, care should be taken to avoid disturbances with clotting factors, calcium and magnesium levels, and any other substances that may be depleted as a result.

CONCLUSION

The impact of AKI on patients and families is often unexpected and, despite new technology, it remains a serious disease with a high mortality rate. Unlike most patients who have had kidney disease for some time, the patient with AKI who requires KRT will not have had the opportunity to have had counselling and the chance to evaluate their condition. The NICE (2023) Clinical Guideline makes specific mention of the need to support patients psychologically and ensure the provision of appropriate patient information and education with regard to prognosis and future treatment options. The key aim of care is to balance humanistic caring skills with the technological and clinical expertise required to optimise the patient's survival and quality of life.

All patients with AKI require a high level of nursing management and the nurse therefore needs to understand the complexities of the illness and understand and manage electrolyte disturbances, disordered fluid status, and nutritional support to maintain protein stores and to reduce the

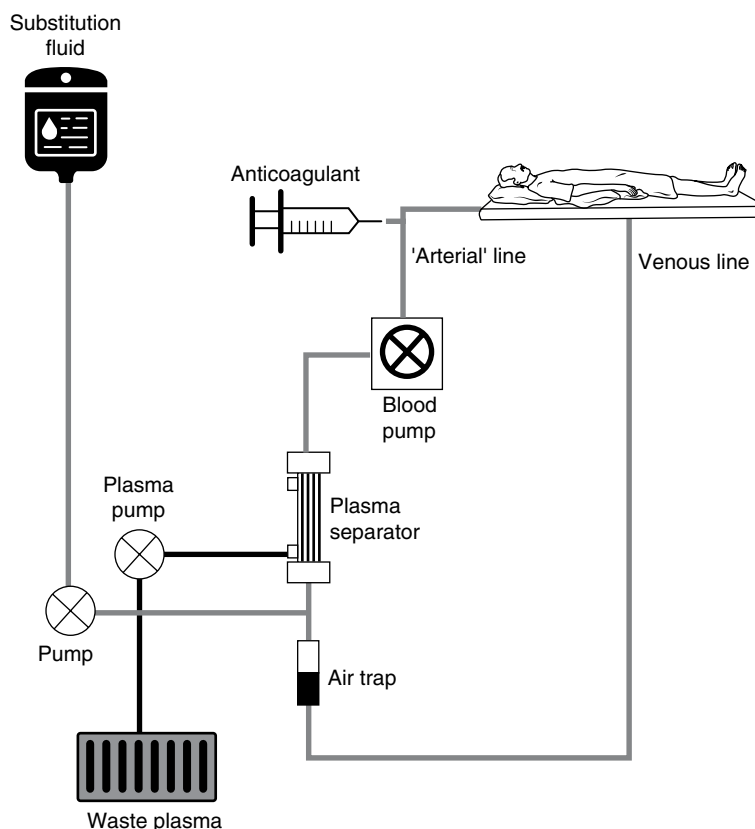


FIGURE 5.6 Plasma exchange.

infection risks. The kidney nurse needs to understand the importance of the AKI classification systems and the relevant treatment guidelines, both national (NICE 2023) and local. The nurse also needs to be able to work with and advise colleagues working in general wards about patients

who may have Stage 1 AKI, aiming to reduce the number that progress further along the AKI spectrum. It is imperative that kidney nurses keep up to date with new technologies and initiatives so they act in a supportive role for their intensive care nursing colleagues.

REFERENCES

- Chan, L., Kumardeep, C., and Aparna, S. et al. (2021). AKI in hospitalized patients with COVID-19. *Journal of the American Society of Nephrology* 32 (1): 151–160.
- Cullis B, Al-Hwiesh A, Kilonzo K, et al. (2021). ISPD guidelines for peritoneal dialysis in acute kidney injury: 2020 update (adults). *Peritoneal Dialysis International*. 41 (1): 15–31. doi:10.1177/0896860820970834
- Drubel, K., Marahrens, B., Ritter, O., and Patschan, D. (2022). Kidney-related outcome in cardiorenal syndrome type 3. *International Journal of Nephrology*. <https://doi.org/10.1155/2022/4895434> (accessed 24 February 2023).
- Fiaccadori, E., Sabatino, A., Brazzoni, R., et al. (2021). ESPEN guideline on clinical nutrition in hospitalized patients with acute or chronic kidney disease. *Clinical Nutrition* 40: 1644–1668.
- Field, M., Pollock, C., and Harris, D. (2010). *The Renal System: Basic Science and Clinical Conditions*, 2e. Edinburgh: Churchill Livingstone.
- Fortin, C., Boucher, A. (2021). Acute Kidney Failure During SARS-CoV-2. *Nephrology Nursing Journal* 48 (5): 493–498.
- Gharaibeh, K., Hamadah, A., El-Zoghby, Z. et al. (2018). Cystatin C predicts renal recovery earlier than creatinine among patients with acute kidney injury. *Kidney International Reports* 3: 337–342.
- Jha, V. (2016). Acute kidney injury. In: *Manual of Nephrology* (ed. P.K. Jha and V. Kher), 111. New Delhi, India: Jaypee Brothers Medical Publishers.
- Kahindo, C., Mukuku, O., and Momeme Mokoli, V. et al. (2022). Predictors of mortality in adults with acute kidney injury

- requiring dialysis: A cohort analysis. *International Journal of Nephrology* <https://doi.org/10.1155/2022/7418955> (accessed 24 February 2023).
- Kerr, M., Bedford, M., Matthews, B., O'Donoghue, D. (2014). The economic impact of acute kidney injury in England. *Nephrology Dialysis Transplantation* 29: 1352–1368.
- Kidney Disease Improving Global Outcomes (KDIGO) Acute kidney injury work group (2012). KDIGO clinical practice guideline for acute kidney injury. *Kidney International (suppl.)* 2: 1–138.
- Levy, J., Brown, E., and Lawrence, A. (2016). *The Oxford Handbook of Dialysis*, 4e. Oxford: Oxford University Press.
- National Institute for Health and Care Excellence (2023). *Acute kidney injury: prevention, detection and management*. <https://www.nice.org.uk/guidance/ng148> (accessed 25 March 2024).
- National Institute for Health and Care Excellence (2017). *Sepsis: recognition, diagnosis and early management*. <https://www.nice.org.uk/guidance/ng51> (accessed 24 February 2023).
- National Confidential Enquiry into Patient Outcome and Death (2009). Adding insult to injury. www.ncepod.org.uk/2009report1/Downloads/AKI_report.pdf (accessed 23 February 2023).
- O'Callaghan, C., Packham, D., and Kingswood, J. (2004). Renal disease, fluid and electrolyte disorders. In: *Medicine*, 2e (ed. J. Axford and C. O'Callaghan), 549–554. Oxford: Blackwell Publishing.
- Pakula, A. and Skinner, R. (2016). Acute kidney injury in the critically ill patient: a current review of the literature. *Journal of Intensive Care Medicine* 31 (5): 319–324.
- Perezella, M.A. (2009). Renal vulnerability to drug toxicity. *Clinical Journal of the American Society of Nephrology* 4: 1275–1283.
- Rangaswami, J., Bhalla, V., and Blair, J. et al. (2019). Cardio-renal syndrome: Classification, pathophysiology, diagnosis, and treatment strategies: A scientific statement from the American Heart Association. *Circulation* 139:16 <https://www.ahajournals.org/doi/full/10.1161/CIR.0000000000000664#:~:text=Cardiorenal%20syndrome%20encompasses%20a%20spectrum,kidney%20interactions%20across%20several%20interfaces.> (accessed 24 February 2023).
- Rennke, H. and Denker, B. (2014). *Renal Pathophysiology: The Essentials*, 4e. Baltimore, MD: Lippincott Williams & Wilkins.
- Ricci, Z., Cruz, D., and Ronco, C. (2007). The RIFLE criteria and mortality in acute kidney injury: a systematic review. *Kidney International* 73 (5): 538–546.
- Rodrigo, E., Suberviola, B., Albines, Z. et al. (2016). A comparison of acute kidney injury classification systems in sepsis. *Nefrologia* 36 (5): 530–534.
- Royal College of Physicians (2017). National Early Warning Score (NEWS) 2. www.rcplondon.ac.uk/projects/outputs/national-early-warning-score-news-2.
- Seck, S.M., Bertrand, D., and Boucar, D. (2011). Current indication of plasma exchange in nephrology: a systematic review. *Saudi Journal of Kidney Disease and Transplantation* 22 (2): 219–224.
- Steddon, S., Chesser, A., Cunningham, J., and Ashman, N. (2014). *Oxford Handbook of Nephrology and Hypertension*, 2e. Oxford: Oxford University Press.
- UK Renal Registry (2020). *Acute Kidney Injury (AKI) in England – A report on the nationwide collection of AKI warning test scores from 2018*. https://ukkidney.org/sites/renal.org/files/AKI_report_FINAL_13072020.pdf (accessed 23 February 2023).
- Van der Slikke, E., Star, B., and van Meurs, M., et al. (2021). Sepsis is associated with mitochondrial DNA damage and a reduced mitochondrial mass in the kidney of patients with sepsis-AKI. *Critical Care* 25(36) <https://doi.org/10.1186/s13054-020-03424-1> (accessed 24 February 2023).
- Wang, H., Muntner, P., Chertow, G., and Warnock, D. (2012). Acute kidney injury and mortality in hospitalized patients. *American Journal of Nephrology* 35: 349–355.
- Weldon, B.C. and Monk, T.G. (2000). The patient at risk for acute renal failure. Recognition, prevention and preoperative optimization. *Anaesthesiology Clinics of North America* 1: 705–717.
- Levy, J., Brown, E., and Lawrence, A. (2016). *Oxford Handbook of Dialysis*, 4e. Oxford: Oxford University Press.
- Tait, D., Williams, C., Barton, D., and James, J. (2022). *Acute and Critical Care in Adult Nursing*, 3e. London: Sage.

FURTHER READING

Field, M., Pollock, C., and Harris, D. (2010). *The Renal System: Basic Science and Clinical Conditions*, 2e. Edinburgh: Churchill Livingstone.

Kellum, J., Bellomo, R., and Ronco, C. (2016). *Continuous Renal Replacement Therapy*, 2e. Oxford: Oxford University Press.

**USEFUL
WEBSITES**

Acute Dialysis Quality Initiative. www.ADQI.net (accessed 24 February 2023).

Hypertension, Dialysis and Clinical Nephrology. www.hdcn.com (accessed 24 February 2023).

KDIGO AKI guidelines. <https://kdigo.org/guidelines/acute-kidney-injury/> (accessed 24 February 2023).

Kidney Care UK, Acute Kidney Injury. <https://kidneycareuk.org/kidney-disease-information/kidney-conditions/acute-kidney-injury-aki/> (accessed 20 April 2024).

London Acute Kidney Injury Network. <https://www.thinkkidneys.nhs.uk/aki/useful-links/london-aki-network/> (accessed 24 February 2023).

UK Kidney Association. www.ukkidney.org (accessed 24 February 2023).

UK Renal Registry. <https://ukkidney.org/about-us/who-we-are/uk-renal-registry> (accessed 24 February 2023).

US Renal Data System. <https://www.niddk.nih.gov/about-niddk/strategic-plans-reports/usrds> (accessed 24 February 2023).

Chronic Kidney Disease and Advanced Kidney Care

Nicola Thomas¹ and Catherine Maina²

¹London South Bank University, London, UK

²St Georges University Hospitals NHS Foundation Trust, UK

LEARNING OUTCOMES

- to understand the categorisation (stages) of chronic kidney disease (CKD).
- to debate the scope of practice of primary care practitioners in managing CKD.
- to review the care and management of patients with mild to moderate CKD.
- to identify new innovations into identification and management of CKD.
- to evaluate best practice guidelines and strategies for advanced care.

INTRODUCTION

This chapter will investigate care and management of those with mild to moderate and advanced kidney disease before kidney replacement therapy (KRT) is required. Kidney nurses are often involved with the technical, monitoring, and evaluative aspects of KRT for those with end-stage kidney disease (ESKD). However, many people may experience reduced renal function for years before needing KRT. This chapter will describe the care and management of people who have mild to moderate and advanced kidney disease and will discuss the published practice guidelines and strategies to guide care for this group of people. New healthcare roles are developing in this area of care, and so the potential for kidney nurses to expand their scope of practice will be discussed.

CHRONIC KIDNEY DISEASE

It was estimated by a CKD audit (Nitsch et al. 2017) that the prevalence of stage 3–5 CKD in the United Kingdom is currently around 5.5–6%, although only a very small minority of this group may eventually require dialysis or

a renal transplant. In the UK in 2021, diabetes remained the most common identifiable primary renal disease (PRD) and continued to account for an increasing proportion of patients starting KRT (31.3%) (UK Renal Registry 2023).

RETHINKING CKD IN THE 2000s: THE NATIONAL SERVICE FRAMEWORK

The National Service Framework (NSF) for Renal Services (Part Two) was published in February 2005 and redirected our thinking towards CKD. The NSF (Part Two) had two quality requirements:

1. *Prevention and early detection of chronic kidney disease.* People at increased risk of developing or having undiagnosed chronic kidney disease, especially people with diabetes or hypertension, are identified, assessed and their condition managed to preserve their kidney function.
2. *Minimising the progression and consequences of chronic kidney disease.* People with a diagnosis of chronic kidney disease receive timely, appropriate

and effective investigation, treatment and follow-up to reduce the risk of progression and complications.

One of the specific recommendations within the NSF made a huge change to the way in which kidney function was measured, and this change in practice will now be explained.

KIDNEY FUNCTION AND ESTIMATED GLOMERULAR FILTRATION RATE

Traditionally, kidney function was assessed by measurement of serum creatinine. Serum creatinine is determined by the rate of production of creatinine, which is dependent on muscle mass as well as the rate at which the kidney excretes it. Because of wide variation in patients' body size, weight, and muscle mass, serum creatinine on its own is an inaccurate measure of kidney function. It is therefore recommended that kidney function in those with mild to moderate CKD (not including acute kidney injury) be assessed by an estimation of glomerular filtration rate (eGFR).

The NSF for Renal Services (2005) recommended the use of the four-variable Modification of Diet in Renal Disease (MDRD) formula to estimate glomerular filtration rate (GFR). Clinical laboratories work out the eGFR based on the results of the serum creatinine, plus the gender and age of the patient. Recent NICE guidelines (2021), however, have recommended that the eGFR calculation is no longer adjusted for ethnicity.

The use of eGFR enables healthcare professionals to evaluate kidney function within the accepted categorisation of CKD. It is important to note that an eGFR of $60 - 89 \text{ ml min}^{-1}$ is only indicative of CKD in the presence of other laboratory or clinical indicators. This reduces the possibility of inappropriately labelling people as having CKD. However, there are some cautionary notes to interpreting eGFR results. The following cautions are adapted from UK Kidney Association guidance (UK Kidney Association 2023a). It is important to bear in mind the following pitfalls and cautions when interpreting the eGFR:

- *eGFR is only an estimate of kidney function.* Significant error is possible. The eGFR is most likely to be inaccurate in people at extremes of body type (e.g. patients with limb amputations, or severely malnourished and morbidly obese individuals).
- *Confidence intervals.* The 90% confidence intervals are quite wide (e.g. 90% of patients will have a true GFR within 30% of their estimated GFR and 98% have measured values within 50% of the estimated value). For an individual patient, however, serial values will be much

more consistent than this, just as creatinine values are (e.g. a 20% fall in a patient's eGFR is certain to reflect an important change).

- *Trend in eGFR.* Identifying trends in eGFR is often more informative than one-off readings. i.e. a progressive fall in eGFR across serial measurements is more concerning than stable readings which don't change over time.
- *Race.* There is increasing concern that the adjustment for ethnicity does not reflect the wide diversity within individuals of Black ethnicity, with the adjustment based on outdated and unfounded biological assumptions for differences between ethnic groups at the expense of better understanding of social and ancestral determinants. In the 2021 NICE chronic kidney disease (CKD) guideline, the recommendation to adjust for ethnicity, present in the 2014 version, has been removed.
- *Not so good near normal.* The equations used for estimating eGFR tend to underestimate normal or near-normal function; therefore, slightly low values (i.e. around the $60 \text{ ml/min/1.73m}^2$ CKD 'cut-off' level) should not be overinterpreted. In this situation repeat testing, looking for a progressive decline in renal function over time, or measurement of cystatin C (a different biomarker of kidney function) may be useful. Additional indicators or renal disease should also be sought in these patients (e.g. urinalysis looking for blood and protein, positive family history of renal disease etc.).
- *Values can differ between laboratories.* Creatinine measurements can differ significantly between laboratories, depending on the methods used to measure it. Furthermore, different laboratories may use a different formula to calculate the eGFR further complicating comparison of eGFR measurements obtained from different laboratories.
- *Creatinine level must be stable.* eGFR calculations assume that the level of creatinine in the blood is stable over days or longer (i.e. steady-state); they are not valid if it is changing. It is therefore not valid in patients with acute kidney injury or in patients receiving dialysis, for example.
- *Age.* MDRD and CKD-EPI equations (see later section on this) are not valid for individuals under 18 years of age.

In summary, a normal range for serum creatinine should no longer be given in isolation when assessing people with mild to moderate CKD, and the patient's management needs to be based on at least two eGFR

results. The widespread use of eGFR has recently contributed to improved recognition of, and appropriate care of, individuals with CKD, including the reduction in late referral rates (now down to around 18%) from primary to secondary care (Byrne et al. 2018).

Since 2010, there has been increasing interest in the use of the CKD Epidemiology Collaboration (CKD-EPI) equation. The CKD-EPI equation has been developed as a more accurate determination of the GFR (Levey et al. 2009) Laboratories in the UK are increasingly using the CKD-EPI equation as recommended in NICE guidance (2021).

STAGING OF CKD

There is now worldwide acceptance of numerical stages or categories of CKD, based on the Kidney Disease Quality Outcomes Initiative (K/DOQI) classification (Kidney Disease Outcome Quality Initiative 2005). In general terms, categories 1–2 do not require specific interventions; categories 3a and 3b are managed in primary care; people with category 4 CKD may require referral to advanced kidney care teams; and people with category 5 usually require some form of KRT (dialysis or transplantation) or conservative management.

In 2012, the international classification was amended and the GFR classification scheme remained with stages 1–5 (stage 3 is split into 3A and 3B), but stages for albuminuria were added: the guideline uses stages A1, A2, and A3 for the degree of albuminuria. This categorisation has been adapted for NICE guidance for CKD (2021). A major change from the previous NICE guideline (2014) was the removal of the recommendation to adjust for ethnicity when calculating the estimated glomerular filtration rate (eGFR) in people from Black ethnic groups.

Table 6.1 shows the NICE (2021) categorisation of CKD.

INCENTIVISATION FOR PRIMARY CARE TO TEST FOR CKD

A contract for general practitioners (GPs) in 2004 enabled GPs to be awarded points (related to income) if their surgery achieved specific indicators within a Quality and Outcomes Framework (QOF). The implementation of the General Medical Services (GMS) contract in 2004 coincided with the drive to implement measures in primary and secondary care for early detection and prevention of the progression of CKD. The inclusion of tests in the Diabetes QOF, such as

Table 6.1 Classification of CKD using GFR and ACR categories (NICE 2021a).

Guide to frequency of monitoring (number of times per year) by GFR and albuminuria category				Persistent albuminuria categories Description and range		
				A1	A2	A3
				Normal to mildly increased	Moderately increased	Severely increased
				<30 mg/g <3 mg/mmol	30–300 mg/g 3–30 mg/mmol	>300 mg/g >30 mg/mmol
GFR categories (ml/min per 1.73 m ²) Description and range	G1	Normal or high	≥90	1 if CKD	1	2
	G2	Mildly decreased	60–89	1 if CKD	1	2
	G3a	Mildly to moderately decreased	45–59	1	2	3
	G3b	Moderately to severely decreased	30–44	2	3	3
	G4	Severely decreased	15–29	3	3	4+
	G5	Kidney failure	<15	4+	4+	4+

GFR and albuminuria grid to reflect the risk of progression by intensity of coloring (green, yellow, orange, red, deep red). The numbers in the boxes are a guide to the frequency of monitoring (number of times per year).

measurement of microalbuminuria and annual testing of creatinine for people with diabetes, has increased the quality of screening and documentation, potentially allowing easier identification for those people with varying stages of CKD caused by diabetes (Roland et al. 2012).

The QOF for CKD was introduced in April 2006 and has been updated each year since. In 2023, only one indicator (maintain a register of patients aged 18 or over with CKD with classification of categories G3a to G5) remains, as previously points were awarded for blood pressure control, urine ACR (albumin–creatinine ratio) testing, and medication prescription. Points are attached to each indicator and determine the sum paid to each practice.

Although recent years have seen an overall improvement in practices achieving blood-pressure and proteinuria targets, there is a large variation in GP practices recording the prevalence of CKD. The CKD Audit Part 1 (Nitsch et al. 2017) identified that there is considerable variation in coding for CKD between GP practices. The proportion of people with CKD stage 3–5 that were uncoded ranged from 0 to 80%, and on average this meant that approximately 70% of those with biochemical evidence of CKD (on the results available) had a CKD code. Amongst the 862 practices with available practice list size data, 4.4% of people over 18 were coded as having CKD stage 3–5. This gave a crude prevalence for coded CKD 3–5 of 3.5%. In 2021–2022, NHS Digital recorded a national prevalence in England of CKD (G3a to G5) of 3.96%.

THE IMPACT OF CLINICAL GUIDELINES FOR MANAGING CKD IN PRIMARY CARE

Since the publication of the first guidelines for managing CKD in primary care in 2005, there remains some scepticism about the impact and significance of diagnosing a patient with CKD, particularly as patients with early disease are often asymptomatic (Brady and O'Donoghue 2010). These findings were supported by Greer et al. (2012), who found that practitioners in the United States reported several patient, provider, and system-level barriers that contributed to poor education about CKD in primary care. More recently, Simmonds et al. (2016) suggested that with the introduction of NICE guidelines in 2014, which focused on the meaning and purpose of CKD monitoring, this may have helped to resolve some of the ethical and moral tensions clinicians expressed regarding the over-medicalisation of patients with a CKD diagnosis. Some remaining uncertainty of CKD as a 'diagnosis' still exists, reflected in the variation of prevalence recording across the UK.

INNOVATION IN MANAGING MILD TO MODERATE KIDNEY DISEASE IN PRIMARY CARE

The aim of primary care management is to prevent or delay progression to ESKD and reduce cardiovascular risk. The Renal Association e-guide for CKD provides a comprehensive introduction to care and management of people with CKD and can be found at UK Kidney Association (2023b).

Understanding the prevalence of CKD means that strategies for identification, assessment, and management need to be developed to help reduce the health burden that CKD poses in the United Kingdom. Not all patients with CKD need to be referred to or managed by a renal team, but these patients are at high risk of cardiovascular disease and should be managed appropriately, irrespective of referral to an advanced kidney clinic. Stable CKD and associated complications, such as cardiovascular risk and anaemia, can be managed in the community or general medical clinics, but timely referrals to renal services are crucial.

Examples of innovative projects to support primary care include employment of specialist renal nurses to work alongside practice and community nurses. The East London Community Kidney Service has instigated a system-wide change in community care of CKD, and employs one clinical nurse specialist for CKD, who educates people with mild to moderate CKD in community settings (Thomas and Rainey 2018). Some renal networks in the UK are replicating this innovation.

Other initiatives, such as computerised systems, can identify patients most at risk of progressive CKD. The ASSIST-CKD project (Gallagher et al. 2017) is based on an intervention by Heart of England Foundation NHS Trust in Birmingham, whereby a community-wide CKD management system has contributed to a decline in the incident rate of KRT and the lowest percentage of patients presenting within 90 days of starting KRT in the UK. The intervention is based on an offline database that integrates laboratory results from blood samples taken in all community and hospital settings relating to the same patient. Graphs of eGFR over time are generated for patients <65 years with an incoming eGFR <50 ml min⁻¹ 1.73 m⁻² and patients >65 years with an incoming eGFR <40 ml min⁻¹ 1.73 m⁻². Graphs where kidney function is deteriorating are flagged by a laboratory scientist or renal nurse and details sent to the GP with a prompt that further action may be needed. Robust evaluation of the intervention is still needed to determine whether this intervention is effective in other healthcare localities and contexts.

In general terms, it appears that local Kidney Networks such as the London Kidney Network and national initiatives have together contributed to the improved

understanding and management of CKD in primary care in the United Kingdom. One such indicator of improved management is late referral to secondary care: the UK Renal Registry (2023) has reported that late presentation (within 3 months of requiring KRT) has continued to fall from 23.9% in 2006 to 18.2% in 2021.

CARE AND MANAGEMENT OF MILD TO MODERATE KIDNEY DISEASE (STAGES 3A–3B)

This section provides a general overview of the care and management of people with category 3a–b CKD, followed by a specific section on care and management of those with diabetes and CKD. The chance of developing CKD increases with age. People of African-Caribbean or South Asian ethnic groups are also more likely to develop kidney disease. CKD appears to progress more rapidly in patients from lower socioeconomic groups. A family history of CKD is also a risk factor. If a 5-year risk of needing renal replacement therapy is greater than 5% (measured using the four-variable Kidney Failure Risk Equation (KFRE)) referral to secondary care is recommended (Kidney Failure Risk Equation 2021). See Box 6.1.

MONITORING OF CKD

Everyone at high risk should have an annual eGFR to ensure that kidney disease is identified when it is still at an early stage. This is important because treatment of mild to moderate kidney disease with appropriate medicine management and changes in lifestyle can slow down kidney damage. Also, early detection and treatment of CKD lessens the chance of it leading to CVD (cardiovascular disease).

How to explain the diagnosis of CKD

Age-related decline in eGFR can be common, so it is important to note that an eGFR in the range 45–59, if stable over time and without any other evidence of kidney damage, is unlikely to progress or develop CKD-related complications.

Words used to explain this need to be chosen carefully. For example, it may be helpful to use the terms *kidney damage* or *reduced kidney function* rather than CKD, as the words *chronic* and *disease* can be frightening. It is also important to explain that kidney damage can be part of the normal ageing process. However, people with stage 3a/b CKD do need to be monitored, and this will be carried out through an annual blood (eGFR) and urine (proteinuria) test. People with CKD should be ‘coded’ (have a Read code), which means their names will appear

on the CKD register in each practice. They should also be informed as such. There are many resources available to inform people about CKD. Kidney Care UK (2023) has a range of resources to support people who have been newly diagnosed with CKD.

Self-management

One of the best ways to effectively manage mild to moderate kidney disease is to empower patients with knowledge of their condition and likely outcomes. Most people with CKD spend the majority of time managing their own condition, supported by healthcare professionals, for only a few hours each year. Both primary and secondary care nurses are well placed to facilitate opportunities for self-management. Key messages include:

- *Urine test.* Remind patients to come for urine tests (ACR) as required, which will help identify if at risk of progressive CKD.
- *Blood test.* Remind patients to come for blood tests to monitor kidney function as required.
- *Blood pressure control.* Explain the importance of BP tablets, not only for blood pressure control but also to delay progression of CKD. Explain the need to report side effects, as high blood pressure is a key factor in the progression of CKD. In adults with CKD and an ACR less than 70 mg/mmol, the blood pressure target is <140/90 mmHg. For those with CKD and an ACR of more than 70 mg/mmol or more, the blood pressure target is 130/80 mmHg.
- *Blood pressure monitoring.* Patients can be instructed to monitor their blood pressure at home, but they will need advice on which machine to buy and training on how to do this.
- *Smoking cessation.* Patients should be supported to stop smoking.
- *Diet.* Remind patients to avoid processed, high-salt, and high-fat foods.
- *Medicine management:*
 - Give advice on buying tablets over the counter (particularly anti-inflammatory drugs).
 - Patients should tell the pharmacist that they have CKD.
- *Lifestyle modification.* Take exercise and keep to ideal weight.
- *Immunisation.* Advise patients on maintaining up-to-date immunisations (influenza, pneumococcus and COVID-19).

Self-management packages

A variety of innovative resources have been developed across the UK to facilitate CKD self-management; one example is from the East London Community Kidney Service (Thomas and Rainey 2018). The pack includes a ‘conversation map’ to be used in both one-on-one and group education sessions, a short and long booklet, plus films in different languages. All resources are freely downloadable at Barts Health NHS Trust (2023).

MEDICINES REVIEW

A medicines review should be undertaken in any newly identified patient with CKD. Patients with CKD should be asked about over-the-counter and herbal medicines to ensure medications are indicated and safe for the individual to take. It is important to emphasise that some medications can affect the kidneys – for example, non-steroidal anti-inflammatory drugs (NSAIDs) such as ibuprofen – so advise patients it is best to check with a pharmacist before purchasing any over-the-counter medicines. Metformin is excreted by the kidneys and has the potential to cause lactic acidosis. Many clinicians prescribe metformin until eGFR is $<30 \text{ ml min}^{-1} 1.73 \text{ m}^{-2}$, when it should be stopped altogether, whilst the dose should be reduced when eGFR $<30\text{--}45 \text{ ml min}^{-1} 1.73 \text{ m}^{-2}$. Special caution should be used when starting metformin in patients who are already on antihypertensive or diuretic therapy, or NSAIDs.

REFERRAL TO SECONDARY CARE

The NICE (2021) guideline gives details on referral to secondary care. A summary of indicators for referral is shown in Box 6.1. Always take into account the individual’s wishes and comorbidities when considering referral.

CARE AND MANAGEMENT OF MODERATE TO SEVERELY DECREASED KIDNEY FUNCTION (STAGE 4)

The care and management of people with stage 4 CKD should be the same as in stage 3a/b, but other considerations should also be considered. Once the eGFR drops to below $20 \text{ ml min}^{-1} 1.73 \text{ m}^{-2}$, the focus should start to be on preparation for KRT.

BOX 6.1

INDICATORS FOR REFERRAL TO SECONDARY CARE

- The 5-year risk of needing renal replacement therapy is greater than 5% (measured using the four-variable Kidney Failure Risk Equation 2021).
- ACR is 70 mg/mmol or more, unless known to be caused by diabetes and already appropriately treated.
- ACR is more than 30 mg/mmol (ACR category A3), together with haematuria.
- eGFR has a sustained decrease in of 25% or more and there is a change in eGFR category within 12 months.–
- There is a sustained decrease in eGFR of $15 \text{ ml min}^{-1} 1.73 \text{ m}^{-2}$ or more per year.
- Hypertension remains poorly controlled (above the person’s individual target) despite the use of at least four antihypertensive medicines at therapeutic doses (see also NICE’s guideline on hypertension in adults).
- There are known or suspected rare or genetic causes of CKD.
- Renal artery stenosis is suspected.

DIABETES MELLITUS

There are special considerations for people who have diabetes and CKD. Good blood glucose control in individuals with type-1 diabetes mellitus has been shown many years ago to prevent or slow down the progression of renal disease (DCCT Research Group 1993). This landmark study demonstrated that a reduction in HbA1c (glycated haemoglobin) from 9.0% to 7.0% was associated with a 39% reduction in the occurrence of microalbuminuria and a 54% reduction in the occurrence of proteinuria over 6.5 years in patients with type-1 diabetes (DCCT Research Group 1993). Early research in type-2 diabetes mellitus indicated that tight blood pressure control was also crucial (United Kingdom Prospective Diabetes Study Group 1998). More recent studies (cited in NICE guidance (2021) for CKD) reflect these findings.

As the kidney function deteriorates, the body’s need for insulin diminishes due to decreased renal insulin clearance and gluconeogenesis. Patients receiving insulin therapy are therefore at risk of developing hypoglycemia. The advanced kidney care nurse specialist monitors the trend of blood glucose every 3 months. The UK Kidney Association (2021) recommends the following targets of glycosylated hemoglobin (HbA_{1c}) in kidney disease (see Table 6.2).

Table 6.2 Glycaemic targets for people with CKD and diabetes mellitus.

	Glycaemic target (HbA1c)	CKD stage and albuminuria
Type-1 diabetes	48–58 mmol/mol (6.5–7.5%) *	CKD stage 2 with variable microalbuminuria
	58–62 mmol/mol (7.5–7.8%)	CKD stages 3–4 and/or albuminuria
	58–68 mmol/mol (7.5–8.5%)	CKD stage 5 – dialysis
Type-2 diabetes	48–58 mmol/mol (6.5–7.5%) *	CKD stages 1–2
	Aim for <52 mmol/mol (6.9%)	
	52–58 mmol/mol (6.9–7.5%)	CKD stages 3–4 May be appropriate with a GLP-1 and/ or SGLT-2 inhibitor-based treatment regime without insulin
	58–68 mmol/mol (7.5–8.5 %)	CKD stages 3–4 and those with CKD stage 5 who are on dialysis. Especially in people with albuminuria who are on an insulin-based regime

* Confirmatory blood glucose or flash glucose monitoring if concern of hypoglycaemia and/or anaemia

SGLT-2 INHIBITORS

Dapagliflozin (an SGLT2 inhibitor) is available on the NHS as a possible treatment to delay progression of CKD in adults. SGLT2 is a co-transporter protein localised primarily in the proximal tubule of the nephron in the kidney, which mediates the active transport of glucose and sodium from the filtrate into the blood, thereby controlling the level of sodium present in the filtrate. In the context of CKD, inhibition of SGLT-2 is anticipated to improve renal outcomes independently of blood glucose. SGLT-2 inhibition also exerts a variety of additional systemic effects which may modify risk factors for the progression of CKD and thereby contribute to reduced kidney damage, including reduced blood pressure, albuminuria and body weight.

An SGLT-2 inhibitor in combination with maximum tolerated RAS/RAAS blockade therapy is therefore now recommended by NICE (March 2022). It is recommended only if:

- It is an add-on to optimised standard care including the highest tolerated licensed dose of angiotensin-converting enzyme (ACE) inhibitors or angiotensin-receptor blockers (ARBs), unless these are contraindicated, and
- The patient has an estimated glomerular filtration rate (eGFR) of 25 ml min⁻¹.73 m⁻² to 75 ml min⁻¹.73 m⁻² at the start of treatment and:
- The patient has type-2 diabetes or
- The patient has a urine albumin-to-creatinine ratio (uACR) of 22.6 mg/mmol or more.

Further guidance from the London Kidney Network on SGLT-2 inhibitor prescribing and use can be found at the London Kidney Network website (2023).

OPTIMAL NUTRITIONAL MANAGEMENT

Management of nutrition, especially the controversial issue of reducing protein intake in CKD, is discussed in Chapter 12. All patients at CKD stage 4 should receive a dietary assessment and be screened for malnutrition.

CONTROL OF SERUM BICARBONATE WITHIN NORMAL LEVELS

As an individual becomes more uraemic, the pH balance in the blood starts to become more acidic. The body's natural response to this is to produce bicarbonate, metabolised from the liver and activated by the kidney, which acts as a buffer to return the pH to more neutral levels. However, if the kidney is defective, this process is thwarted, and supplementary bicarbonate may be administered. The safest way to control bicarbonate balance is with dialysis for patients who have started dialysis. For those with advanced kidney disease (pre-dialysis), the bicarbonate level can be safely controlled by the use of oral sodium bicarbonate. Rectifying low bicarbonate levels can be an effective way of balancing pH and helping to reduce serum potassium, hence correcting the metabolic acidosis. Intractable hyperkalemia can be an indication for starting dialysis.

MANAGEMENT OF BONE DISEASE

Renal disease causes an abnormality of vitamin D metabolism, causing deficient calcium levels, skeletal damage, and bone pain. Refer to Chapter 2 for further information on the underlying physiological processes. The aim of care is to keep calcium and phosphate levels within normal

ranges, preventing hyperparathyroidism. After correcting the acidosis, plasma phosphate and calcium levels can be controlled with oral phosphate binders, calcium supplements, and dietary changes. National Institute for Health and Care Excellence (NICE) Guideline NG203, *Chronic Kidney Disease: Assessment and Management*, includes a specific section (1.11) on managing hyperphosphataemia (NICE 2021a). See Chapter 12 for more discussion.

CONTROL OF ANAEMIA

Anaemia in CKD is usually normocytic and normochromic, and due to primary causes, such as reduced production of erythropoietin, uraemic toxins inhibiting erythropoiesis, and haemolysis due to uraemic changes to the red cell membrane. The individual will become more anaemic as renal disease progresses, as three types of cells in the blood are affected:

- erythrocytes – causing anaemia;
- leukocytes – causing immunosuppression;
- platelets – causing bleeding tendencies.

NICE guidance (2021) was updated because of the need to review evidence in several areas that provide challenges for clinicians managing anaemia in CKD, namely people who consistently fail to respond to erythropoietic stimulating agents (ESAs) and the role and management of iron deficiency.

There are some general principles for managing anaemia caused by CKD: investigations should start if haemoglobin (Hb) levels fall to 110 g/litre or less or if patients develop symptoms attributable to anaemia (such as tiredness, shortness of breath, lethargy, and palpitations). Other causes of anaemia need to be investigated, such as gastrointestinal problems which can cause bleeding, as other factors may mimic anaemia of CKD and perhaps lead to a misdiagnosis of non-response to ESA or iron therapy. Treatments include offering ESA therapy to adults, children, and young people who are likely to benefit in terms of quality of life and physical function; avoiding blood transfusions if possible in patients whom kidney transplant is a treatment option; discussing the choice of ESA with the patient when starting treatment and at subsequent review; and taking into account the person's dialysis status, the route of administration, and the local availability of ESAs.

The correction to *normal* levels of Hb with ESAs is not usually recommended in people with anaemia of CKD. The aspirational Hb range should be maintained between 100 and 120 g l⁻¹ for adults, young people, and children aged 2 years and older. To keep the Hb level within the aspirational

range, it is preferable to not wait until Hb levels are outside the aspirational range before adjusting treatment (take action when Hb levels are within 5 g l⁻¹ of the range's limits).

It is also important to monitor iron status, and iron therapy should be offered to people receiving ESA maintenance therapy to keep:

- percentage of hypochromic red blood cells less than 6% (unless serum ferritin is greater than 800 µg l⁻¹);
- reticulocyte Hb count or equivalent tests above 29 pg (unless serum ferritin is greater than 800 µg l⁻¹);
- transferrin saturation level above 20% and serum ferritin level above 100 µg l⁻¹ (unless serum ferritin is greater than 800 µg l⁻¹).

In advanced kidney care (predialysis stage), levels of the above should be monitored every three months. If patients have a normal full blood count, there is little benefit in checking iron status. See NICE (2021) guidance for further information on iron therapy for people who are iron deficient and are/are not receiving ESA therapy. In all cases discuss the results of the iron therapy with the patient or family and offer ESA therapy if needed.

Iron stores, Vitamin B12, and folate levels need to be adequate before commencing ESA therapy.

CONTROL OF GASTROINTESTINAL DISORDERS

These disorders are common in CKD, especially as the individual approaches the need for dialysis. The person may experience anorexia, nausea and vomiting, hiccups, a metallic taste in the mouth, and, for those with diabetes, exacerbation of gut complications presenting as episodes of diarrhoea. Urea is excreted in the gut and broken down, releasing ammonia, which acts as an irritant. Constipation can be common in end-stage kidney disease (ESKD) especially with oral iron, reduced fluid intake and less physical activity.

TREATMENT OF DERMATOLOGICAL DISORDERS

Generalised uraemic pruritus (itching) is a distressing symptom in persons with CKD, with often little relief from drugs. Deposits of calcium and phosphorus in the skin and sweat glands excreting urea are thought to be the causative factors of pruritus, but dry skin and drug allergies must not be overlooked as causes. Platelet defects and capillary permeability, both complications of advanced kidney disease, can cause bleeding and bruising of the skin, especially if

there is continued scratching. Many persons with advanced kidney disease have a yellow tinge to their skin that is a combined result of hypermelanosis and the deposition of pigments in the skin (uro-chrome and carotene) that are usually excreted by the kidneys.

Although medications may be of some help (Rayner et al. 2013), commencement of dialysis may be the only long-term relief. Some non-pharmacologic measures may be attempted like using hypoallergenic detergents and using cool water to bathe. Cotton clothes are preferred over other materials that may irritate the skin. Local antihistamine creams can also be tried especially in patients who are on the conservative care pathway (see Chapter 10).

CONTROL OF VOLUME DISORDERS

During the progression of kidney disease, some nephrons remain intact whilst others continue to be destroyed. The remaining undamaged nephrons hypertrophy and produce an increased volume of filtrate with increased tubular reabsorption, even though there is a reduction in the GFR. This process allows the kidney to continue to function until three-quarters of the nephrons are destroyed. In persons with CKD with blood urea levels above 40 mmol/litre, the solute load becomes greater than can be reabsorbed, producing an osmotic diuresis accompanied by polyuria of up to 3 l in a 24-hour period. The urine is dilute as the kidney's concentration ability is lost and the person will have nocturia. As more nephrons are destroyed, oliguria with the retention of waste products is evident. The individual develops a wide range of biochemical, haematological, and endocrine disorders and the clinical features of fluid overload.

Changes in fluid allowance may be required in association with diuretics. Loop diuretics such as furosemide will increase sodium excretion from the kidney and so prevent sodium retention. During episodes of polyuria, volume replacement should be administered to prevent further reduction in renal perfusion and worsening of kidney function. When volume overload is unresponsive to treatment the commencement of dialysis is indicated.

CONTROL OF POTASSIUM DISORDERS

Excess potassium is normally removed by renal excretion, but as CKD progresses, excretion of urinary potassium decreases because of a reduced GFR caused by tubular defects in diseases such as diabetes mellitus, ultimately resulting in hyperkalaemia. Hyperkalaemia (indicated as a potassium level of above 6.0 mmol/litre) can occur in CKD following episodes of acute illness,

infection, or non-adherence to dietary restrictions. Chronic metabolic acidosis also causes potassium to shift out of the cells and into the extracellular fluid, giving rise to hyperkalaemia.

If metabolic acidosis is present, this should be corrected first, and this will then help to reduce the serum potassium to within safe limits. If chronic hyperkalaemia is present, dietary advice may be indicated, so high-potassium foods are avoided (see Chapter 12).

Potassium-sparing diuretics should usually be discontinued as these drugs block the distal potassium transfer so that potassium is retained. If hyperkalaemia persists, this should be monitored very closely and managed in one of two ways – either conservatively or with dialysis. Conservative management of hyperkalaemia may involve the use of exchange resins (e.g. calcium resonium or sodium zirconium). Oral resins are not absorbed, but exchange potassium for calcium or sodium from the gastrointestinal tract. The choice of calcium or sodium depends on the level of hypercalcaemia or fluid overload in the individual.

In 2021, NICE issued a technology appraisal for patiromer, which is treatment for people with hyperkalaemia. It can be used for adults with chronic kidney disease or heart failure, either in emergency care alongside standard care for acute life-threatening hyperkalaemia or for persistent hyperkalaemia if they are able to have RAAS inhibitors.

Patiromer is recommended as an option for treating hyperkalaemia in adults only if they:

- have a confirmed serum potassium level of at least 6.0 mmol/litre; and
- are not taking, or are taking a reduced dosage of, a renin-angiotensin-aldosterone system (RAAS) inhibitor because of hyperkalaemia; and
- are not on dialysis.

CONTROL OF ACID-BASE BALANCE

In normal health, acid-base balance is maintained by the excretion into the renal tubules of excess acid (hydrogen, or H^+ , ions) where the following processes then take place:

- Filtered bicarbonate is reabsorbed.
- There is increased production of ammonia that combines with H^+ ions and is then excreted in the form of ammonium salts.
- A titratable acid is formed.
- Tubular fluid pH is reduced.

In CKD, a mild metabolic acidosis may be present as normal renal tissue is not sufficient to perform the above functions efficiently. Metabolic acidosis may also be worse in persons who have renal tubular acidosis.

The individual will present with the following symptoms:

- *Low blood pH.* Blood pH is less than 7.35.
- *Hyperkalaemia.* Metabolic acidosis shifts potassium from the cells into the extracellular fluid.
- *Signs of renal bone disease.* Metabolic acidosis reduces the bone carbonate buffers, allowing calcium to be lost from the bones. Calcium is more soluble in an acid environment.
- *Gasping for breath caused by acidosis.* The person is attempting to breathe off the excess acid through expired carbon dioxide.

Intravenous sodium bicarbonate may correct acidosis, but the sodium may cause hypernatraemia, leading to fluid retention and hypertension. Oral sodium bicarbonate can be safely prescribed to treat acidosis. Essentially, metabolic acidosis indicates ESKD; the most efficient and safest way to treat it is with dialysis.

DISORDERS OF THE CENTRAL NERVOUS SYSTEM

In advanced kidney disease, nervous system dysfunction can cause numerous mental disabilities such as poor memory function, loss of concentration, and slower mental ability. Physical disabilities result in peripheral neuropathies affecting the legs and feet and may result in 'restless legs' and paraesthesia. More serious neurological problems are rarely seen these days, where there is fluid overload and hypertension in advanced kidney disease, in the form of convulsions and cerebral oedema. A 'uraemic flap' may be seen in very toxic patients, where the hands involuntarily flap from the wrists. Other electrolyte disorders (such as hyper- or hypocalcaemia) also cause shaking, or an involuntary reflex, when nerve points are stimulated. All these symptoms and complications can be avoided with the introduction of timely dialysis.

SEXUAL DYSFUNCTION

In women, the loss of sexual function may take the form of infertility due to amenorrhoea and other menstrual abnormalities. Loss of libido may be present. There is also risk to

the mother's health, as it is possible that progression to ESKD will accelerate because of the extra workload on damaged kidneys.

In men, the incidence of infertility and impotence increases with age and the advancement of CKD. There are multiple causes of impotence, which include poor nutrition, anxiety, side effects of antihypertensive drugs, and reduced plasma testosterone. The individual and partner should be given ample opportunity to express fears and talk about symptoms that are causes for concern.

With the wider use of erythropoietin to correct anaemia, fewer women with decreased renal function are experiencing loss of fertility and amenorrhoea. Successful pregnancy for couples where at least one partner has a degree of kidney disease is becoming more common, although it requires careful planning and monitoring for a successful outcome. More than 1,000 pregnancies have been reported in women receiving dialysis (Piccoli et al. 2016). There is a strong relationship between the intensity (frequency and duration) of dialysis sessions and positive pregnancy results. Piccoli et al. (2018) in their editorial for World Kidney Day 2018 raised interesting questions about pregnancy in CKD. They asserted that the presence of any degree of CKD has a negative effect on pregnancy, plus there is an increase in risk of CKD progression post-partum, ethical issues around conception, and maintenance of pregnancies are raised for the healthcare team and the patient.

EDUCATION IN ADVANCED KIDNEY CARE

Preparation for kidney replacement therapy (KRT) can be supported by the use of the Kidney Failure Risk Equation (KRFRE) to guide patients and the renal team. A risk of 40% and above calls for active access preparation. This can take the form of arteriovenous fistula creation if haemodialysis is the chosen modality. The KRFRE can also help patients in making positive lifestyle changes that delay progression of kidney disease and prepare for KRT, avoiding unplanned starts.

The need for good education and preparation of the individual and the family at all stages of CKD, potentially heading towards ESKD, cannot be underestimated (van Eck van der Sluijs et al. 2021). The psychological aspects of dealing with this long-term illness have been discussed in Chapter 4, but it is worth reiterating the importance of education and information as part of the preparation process. It is essential that the patient and renal team work in collaboration, not only to ensure the best care possible for the person, but also for the renal team to understand the patient and family perspective.

For some, it is very important to be able to continue in their present employment, and so education about renal replacement therapies should include practical consideration of how dialysis is to be performed. For example, peritoneal dialysis that people can perform for themselves, or some form of home dialysis programme, is key to maintaining employment status.

Education during the pre-dialysis stage is crucial, and this involves not just clear, understandable information about the condition and the treatment or support options but also prompts that help them think about what the different options might mean for them. These prompts are called patient decision aids (PDAs) and are designed to help clinicians to actively engage patients in the decision-making process. Decision aids include several components with relevant information that help patients to remember facts and make deliberate choices between two or more treatment options. Decision aids for people with kidney disease have been developed (e.g. YoDDA 2024), but NICE (2018) guidance has suggested that further research into PDAs is needed. One of the research recommendations from the NICE (2018) guidelines asks what the clinical effectiveness and cost effectiveness is of using decision aids in the context of KRT. For some, the thought of attempting to understand any aspect of the KRT process is daunting and overwhelming. This may be due to the immediacy of the circumstances in which they commenced KRT, or indeed their sense of control and unique personal characteristics, which mean the understanding healthcare professionals should take the lead in directing care. This in no way means that the individual absolves responsibility or plays no part in any of the decision-making processes about care and treatment.

For advanced kidney care preparation to be effective, influences on learning such as cultural and religious beliefs about the context of CKD must be taken into consideration. Indeed, misunderstanding and misinterpretation by the individual and their family may have more to do with the way information is presented (e.g. jargon used) by healthcare professionals. For many patients the cultural and religious contexts of health are crucial in shaping how far healthcare advice is accepted. The renal unit is a confusing place where the individual has to make sense of their symptoms and proposed treatment plan. Patients also have to work through the stages of grief of losing an old life, and also have to realign the new (renal) life with personal ideology and life goals.

The ultimate skill that any renal healthcare professional can hope to achieve in the care of those approaching KRT is

to be able to gain an understanding of each individual. That person is unique as regards personal hopes and aspirations for the future, the ability to understand the care and treatment strategies that lie ahead, and how the individual wishes to be involved in that care delivery. All too often, renal professionals of all kinds can be very focused on the pathological and technical aspects that dominate their understanding of their role as a renal practitioner. For the individual approaching KRT, the priorities may be quite different, so it is important to start providing information very early on, at least one year before dialysis is required.

Combes et al. (2017) support this view. The study argues for a more individualised approach to PDE (predialysis education), which is more like counselling than education and demands a higher level of skill and training for specialist PDE staff. The study concludes that even if these improvements are made to PDE, not all patients will benefit, because some find decision-making in the predialysis period too complex or are unable to engage with education due to illness or emotional distress. A co-produced study (Thomas et al. 2016) in two NHS Trusts also supported the assertion that predialysis education programmes (PDEPs) should improve on the quality of the information provided, especially how daily living can be affected by dialysis.

A scoping review (van Eck van der Sluijs 2021) identified good practices for pre-dialysis education, including the provision of complete and objective predialysis education, assisting people receiving PD on how to adequately perform PD, educating patients who choose HD on self-management, and talking with patients about their prognosis. The good practices for dialysis focus mainly on dialysis access devices and general quality improvement of dialysis care.

It is also important to always be aware that there may be those for whom initiation of dialysis may not be feasible or preferable. The option of not commencing dialysis at all is discussed in detail in Chapter 11.

SHARED DECISION-MAKING

Shared decision-making advocates for patients and their families to take an active role in their own treatment. In the advanced kidney care clinic, this may assume the sharing of information with patients regarding KRT several times before they choose a modality. It is critical that healthcare workers speak in lay terms to enhance understanding of the otherwise complex medical language.

Elwyn et al (2017) proposes a revised the three-talk model structure that renal specialist nurses can use to support patients in their decision-making (Figure 6.1).

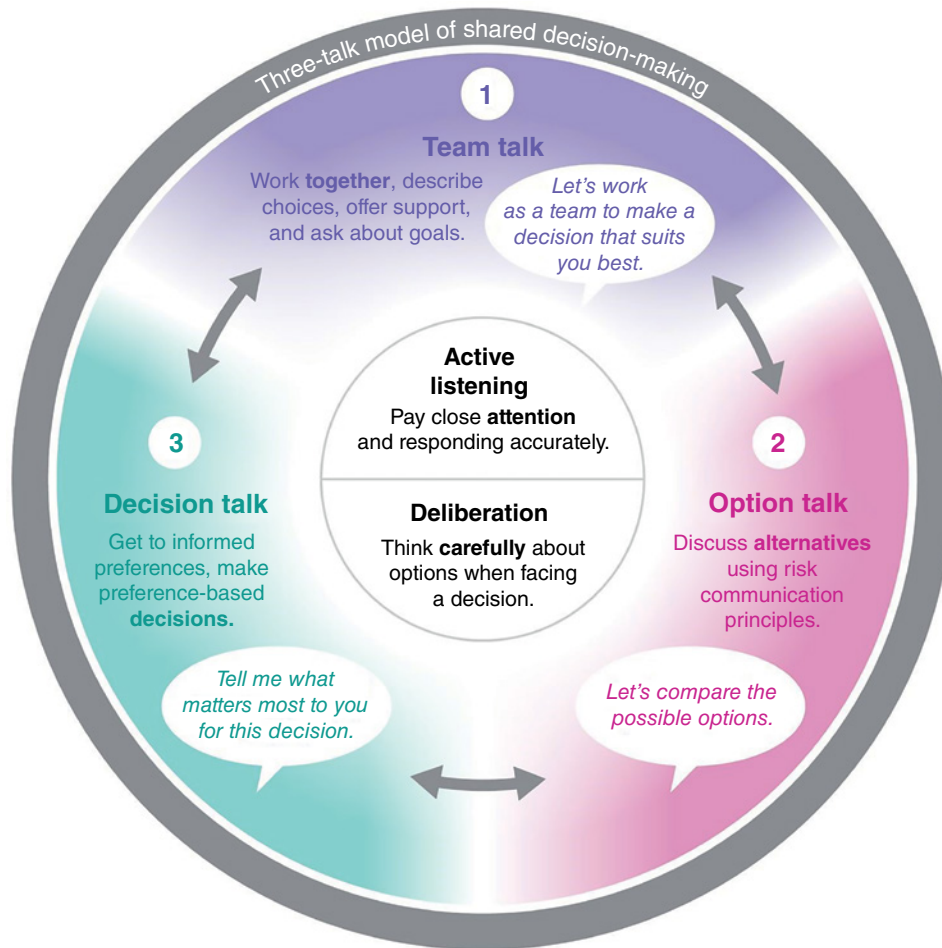


FIGURE 6.1 The three-talk model of shared decision-making (Elwyn 2018 / Elsevier). A three-talk model for shared decision-making: multistage consultation process | The BMJ.

Team talk

This might be the first encounter between the patient and the advanced kidney care (AKC) nurse specialist. Patients may still be in denial about the kidney disease especially when they feel no symptoms at all. The referral may be from the general nephrology team, who have been monitoring the decline of kidney function, for from diabetes clinics, urology or other departments.

Fears and anxieties over poor kidney function are real concerns. Some patients may have looked up information online and therefore have some idea on what to expect. Others might know someone with ESKD, which may influence their decisions, and it is vital to address what is important and specific to the patient.

People often feel powerless and out of control when diagnosed with a long-term condition. This is a

great opportunity to meet other members of the AKC team like the dietitian or renal psychologist. Reassuring patients that they have control over the management of ESKD is of great significance in this initial meeting. NICE guidance (2018) recommended shared decision-making, including:

- clinical preparation;
- psychosocial evaluation, preparation and support;
- the person's individual preferences for type of KRT and when to start;
- how decisions are likely to affect daily life.

Further assessment by a clinical psychologist or psychiatrist is recommended for adults being considered for a

transplant if risk factors for poor outcomes have been identified. These may include:

- lack of social support;
- neurocognitive issues;
- non-adherence (medicines, diet, hospital appointments);
- poor understanding of process and complexities of treatment;
- poorly controlled mental health conditions or severe mental illness;
- substance misuse or dependence.

Option talk

Discuss with patients and their carers (or next of kin) all the modalities of KRT, either 1–1 or in group education sessions. The options and the implications of each modality, for example how the modality can change a patient's routine and quality of life is important. Also provide time to discuss the implications of doing nothing (no dialysis) and what that means to the patient (see Chapter 10).

It is critical to tailor the educational methods to meet individual needs – for example, using an interpreter or provide a sign language interpreter. It is also important to encourage patients to write down questions to ask at the next stage.

Decision talk

Here the patient is supported to make a decision on what modality suits them best. The AKC nurse can now refer to the vascular access team or the surgical team based on the modality decided. Depending on the modality, referral can also be made to the conservative or supportive care nurse specialists for further input.

The three-talk model is not a linear process but a cyclic, repetitive experience. The model serves as a guide; the onus is upon the AKC nurse specialist to tailor it to fit the patient's need. Further information on shared decision-making can be found in NICE guidance (NICE 2021b).

ADVANCED KIDNEY CARE EDUCATION: PRACTICAL ASPECTS

The advanced kidney care (AKC) clinic was previously known as pre-dialysis or low clearance clinic. Advanced kidney care refers to the interventions taken when the eGFR is ≤ 20 ml/min/1.73m². The aim of the AKC nurse is

to prevent an unplanned dialysis start, plan for dialysis and/or kidney transplantation as well as helping the patient navigate the various options of KRT. Members of the AKC team include specialist nurses (AKC, transplantation, anaemia vascular access), kidney doctors, dietitians, social workers, and renal psychologists. The UK Kidney Association (2022) recommends a “timely, tailored, community based, peer educator, multi-professional team involvement” in AKC decision-making. A structured AKC referral pathway enhances timely vascular access creation whilst allowing additional time for any vascular access intervention if needed.

There are many benefits to running a structured AKC clinic. Some units run group education sessions for patients and their families, but since the COVID-19 pandemic these may have scaled down to the use of one-to-one and virtual education sessions.

NICE (2021) guidelines recommend starting advanced kidney care education programs at least a year before the need for kidney replacement therapy (KRT). Patients and their families need time to process the otherwise complex medical language involved in ESKD and KRT; however, it is not unusual for patients who do not remember the education they received (Judith et al. 2022).

A summary of the content for implementing AKCC pre-dialysis education programmes is shown in Box 6.2.

There are many national or pharmaceutical-funded resources that could be included in an education programme. Goovaerts et al. (2015) has identified questions that nurses should ask when assessing the quality and suitability of a material/resource:

- Will I feel comfortable using it?
- Will it enhance the understanding of disease and treatment?
- Will it present the consequences of the patient's decision?
- Will it encourage the patient to use their own reasoning?
- Will it help the patient to develop realistic expectations?
- Will it supplement rather than replace the information provided by the educator?

WHEN SHOULD DIALYSIS COMMENCE?

NICE (2018) recommends starting dialysis by the impact of symptoms of uraemia on daily living, or biochemical measures or uncontrollable fluid overload, or at an estimated glomerular filtration rate (eGFR) of around 5 to 7 ml/

BOX 6.2

SUGGESTED CONTENT FOR PRE-DIALYSIS EDUCATION PROGRAMMES FROM NICE (2018) GUIDELINES FOR RENAL REPLACEMENT THERAPY AND CONSERVATIVE MANAGEMENT

Patients should be provided with information about treatments and how they may affect lifestyle:

- What treatments involve (e.g. availability of assistance, time that treatment takes place, and number of sessions per day/week)*
- Potential benefits, such as the benefits of adherence to treatment regimens and the potential consequences of non-adherence
- Potential adverse effects, their severity, and how they may be managed
- Likely prognosis on dialysis, after transplant, or with conservative management
- Transplant listing process (when appropriate)
- Switching the modality of KRT and the possible consequences (i.e. the impact on the person's life or how this may affect future treatment or outcomes)
- Reviewing treatment decisions
- Stopping treatment and planning end-of-life care
- Information about how treatments may affect lifestyle
- The person or carer's ability to carry out and adjust the treatment themselves
- Possible impact of dietary management and management of fluid allowance
- How treatment may fit in with daily activities such as work, school, hobbies, family commitments, and travel for work or leisure
- How treatment may affect sexual function, fertility, and family planning
- Opportunities to maintain social interaction
- How treatment may affect body image
- How treatment may affect physical activity (e.g. whether contact sports should be avoided after transplantation, whether swimming should be avoided with peritoneal dialysis)
- Whether a person's home will need to be modified to accommodate treatment
- How much time and travel treatment or training will involve
- Availability of transport
- Flexibility of the treatment regimen
- Whether any additional support or services might be needed

* Treatments include KRT, conservative management, and dietary intervention.

$\text{min}^{-1}/1.73 \text{ m}^{-2}$ if there are no symptoms. It is important to ask patients specifically about their symptoms, as many patients may say they are well to delay the start of dialysis. NICE (2018) has listed possible symptoms to consider, including breathlessness, fatigue, insomnia, itching, lethargy, pain, poor appetite, swelling, taste changes, thirst, weakness, and weight loss/gain. Other symptoms are gastrointestinal/urological, musculoskeletal, neurological, and psychological/behavioural.

CONCLUSION

Having reviewed the guidelines and strategies for supporting the individual with CKD, it can be seen that there has been an evolution in this area of care, especially concerning patient decision-making. The emphasis on

shared decision-making empowers patients to take charge of their own care.

Primary care practitioners and non-specialist health-care professionals are now increasingly expected and encouraged to be involved in CKD care delivery. There have been developments in the management of eGFR, anaemia, nutrition, and patient education, and new clinical guidelines for managing CKD. The use of KRFE will have an impact on how timely the referral from primary care will be. Peer education groups and remote virtual consultations are all new entrants into CKD and AKC delivery.

Future development of approaches to CKD needs to include cultural and religious considerations when these areas of a person's life clearly affect the presenting biomedical symptoms, as well as psychological adaptation and coping strategies. Nurses in particular have many professional skills that could be harnessed to address these issues.

REFERENCES

- Arora, P., Rajagopalan, S., Patel, N. et al. (2012). The MDRD equation underestimates the prevalence of CKD among Blacks and overestimates the prevalence of CKD among Whites compared to the CKD-EPI equation: a retrospective cohort study. *BMC Nephrology* 13 (1): 4.
- Barts Health NHS Trust (2023). Educational materials for CKD. <https://bartshhealth.nhs.uk/renal> (accessed 7 August 2023).
- Brady, M. and O'Donoghue, D. (2010). The role of primary care in managing chronic kidney disease. *The British Journal of General Practice* 60 (575): 396.
- Combes, G., Sein, K., and Allen, K. (2017). How does pre-dialysis education need to change? Findings from a qualitative study with staff and patients. *BMC Nephrology* 18: 1–11.
- Crinson, I., Gallagher, H., Thomas, N. et al. (2010). How ready is general practice to improve quality in chronic kidney disease? A diagnostic analysis. *The British Journal of General Practice* 60 (575): 403.
- Davison, J.M. and Lindheimer, M.D. (2011). Pregnancy and chronic kidney disease. *Seminars in Nephrology* 31 (1): 86–99.
- DCCT Research Group (1993). Diabetes Control and Complications trial (DCCT): the effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin dependent diabetes mellitus. *New England Journal of Medicine* 329 (14): 977–986.
- Department of Health (2005). *National Service Framework for Renal Services: Chronic Kidney Disease, Acute Renal Failure and End of Life Care (Part Two)*. London: HMSO.
- Diabetes Control and Complications Trial Research Group (1993). The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine* 329: 977–986.
- Gallagher, H., Methven, S., Casula, A., et al. (2017). A programme to spread eGFR graph surveillance for the early identification, support and treatment of people with progressive chronic kidney disease (ASSIST-CKD): protocol for the stepped wedge implementation and evaluation of an intervention to reduce late presentation for renal replacement therapy. *BMC Nephrology* 18: 1–10.
- Goovaerts, T., Isnard, B.C., Crepaldi, C. et al. (2015). Continuing education: preparing patients to choose a renal replacement therapy. *Journal of Renal Care* 40 (1): 62–75.
- Greer, R.C., Crews, D.C., and Boulware, L. (2012). Challenges perceived by primary care providers to educating patients about chronic kidney disease. *Journal of Renal Care* 38 (4): 174–181.
- Honey, P. and Mumford, A. (1986). *The Manual of Learning Styles*. London: Peter Honey Associates.
- Kidney Care UK (2023). Newly diagnosed? <https://kidneycareuk.org/kidney-disease-information/stages-of-kidney-disease/just-diagnosed-with-kidney-disease/> (accessed 7 August 2023).
- Kidney Disease Outcome Quality Initiative (K/DOQI) (2005). K/DOQI clinical practice guidelines for chronic kidney disease: evaluation, classification, and stratification. *American Journal of Kidney Diseases* 39 (suppl. 1): S1–S266.
- The Kidney Failure Risk Equation (2021). <https://kidneyfailurerisk.co.uk> (accessed 15 August 2023).
- Levey, A.S., Stevens, L.A., Schmid, C.H., et al. (2009). A new equation to estimate glomerular filtration rate. *Annals of Internal Medicine* 150 (9): 604–612.
- London Kidney Network. *Guidelines on Chronic Kidney Disease (CKD) Coding in Primary Care London Kidney Network Expert Consensus* (London: National Health Service, 2003), slides 7–10, <https://selondonccg.nhs.uk/wp-content/uploads/2023/04/LKN-CKD-Coding-Guidelines-19.4.23-Final-v2.1.pdf> (accessed 17 October 2023).
- National Institute for Health and Care Excellence (NICE) (2018). *Renal Replacement Therapy*. NICE guideline NG107 (London: NICE). <https://www.nice.org.uk/guidance/NG107> (accessed 24 April 2019).
- National Institute for Health and Care Excellence (NICE) (2020). *Patiromer for Treating Hyperkalaemia*. Health Technology Appraisal TA623 (London: NICE). <https://www.nice.org.uk/guidance/ta623/> (accessed 17 October 2023).
- National Institute for Health and Care Excellence (NICE) (2021a). *Chronic Kidney Disease: Assessment and Management*. NICE Guidance NG203 (London: NICE). <https://www.nice.org.uk/guidance/ng203> (accessed 7 August 2023).
- National Institute for Health and Care Excellence (NICE) (2021b). *Shared Decision Making*. NICE Guidance NG197 (London: NICE). <https://www.nice.org.uk/guidance/ng203> (accessed 15 August 2023).
- National Institute for Health and Care Excellence (NICE) (2022). *Dapagliflozin for Treating Chronic Kidney Disease*. Health Technology Appraisal TA775 (London: NICE). <https://www.nice.org.uk/guidance/TA775/> (accessed 17 October 2023).
- Nitsch, D., Caplin, B., Hull, S., et al. (2017). First National CKD Audit Report. Available at www.lshtm.ac.uk/files/ckd_audit_report.pdf (accessed 20 June 2018).
- Piccoli, G.B., Minelli, F., Versino, E., et al. (2016). Pregnancy in dialysis patients in the new millennium: a systematic review and meta-regression analysis correlating dialysis schedules and pregnancy outcomes. *Nephrol Dial Transplant* 31: 1915–1934.

- Piccoli, G.B., Alrukhaimi, M., Liu, Z., et al. (2018). Women and kidney disease: reflections on world kidney day 2018. *Journal of Renal Care* 44 (1): 3–11.
- Rayner, H., Baharani, J., Smith, S., et al. (2013). Uraemic pruritus: relief of itching by gabapentin and pregabalin. *Nephron Clinical Practice* 122 (3–4): 75–79.
- Roland, M., Guthrie, B., and Thomé, D.C. (2012). Primary medical care in the United Kingdom. *Journal of the American Board of Family Medicine* 25 (suppl. 1): S6–S11.
- Simmonds, R., Evans, J., Horwood, J., et al. (2016). Understanding tensions and identifying clinician agreement on improvements to early-stage chronic kidney disease monitoring in primary care: a qualitative study. *BMJ Open* 6 (3): e010337.
- Thomas, N. and Rainey, H. (2018). Innovating and evaluating education for people with kidney disease. *Journal of Kidney Care* 3 (2): 114–119.
- UK Kidney Association (2021). Clinical practice guidelines for management of hyperglycaemia in adults with diabetic kidney disease. <https://ukkidney.org/sites/renal.org/files/Management-of-hyperglycaemia-in-adults%20-with-DKD.pdf> (accessed 7 August 2023).
- UK Kidney Association (2023a). About eGFR. <https://ukkidney.org/health-professionals/information-resources/uk-eckd-guide/about-egfr> (accessed 29 June 2023).
- UK Kidney Association (2023b). The UK eCKD guide. <https://ukkidney.org/health-professionals/information-resources/uk-eckd-guide> (accessed 7 August 2023).
- United Kingdom Prospective Diabetes Study Group (UKPDS). (1998). Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes: UKPDS 38. *British Medical Journal* 317: 703–713.
- UK Renal Registry (2023). UK Renal Registry 25th Annual Report – data to December 31, 2021, Bristol, UK. Available from <https://ukkidney.org/audit-research/annual-report>.
- van Eck van der Sluijs, A., Vonk, S., van Jaarsveld, B.C., et al. (2021). Good practices for dialysis education, treatment, and eHealth: A scoping review. *PLoS ONE* 16 (8): e0255734.
- Yorkshire Dialysis Decision Aid (YoDDA) (2024). Background. University of Leeds. <https://www.yodda.leeds.ac.uk/Survey/Introduction>.

RESOURCES

Kidney Care UK educational resources <https://www.kidneycareuk.org/about-kidney-health/newly-diagnosed/> (accessed 15 August 2023).

NHS web page on CKD <https://www.nhs.uk/conditions/kidney-disease/living-with/> (accessed 15 August 2023).

LEARNING OUTCOMES

- to define haemodialysis and how it replaces the functions of the kidney.
- to examine the components of the haemodialysis prescription and when this may need adjustment.
- to explore vascular access options for haemodialysis treatments and how to care for these, minimising complications.
- to explain the nursing care required to look after patients during haemodialysis, including recognition of complications.
- to explore the patient's experience of haemodialysis.

INTRODUCTION

Dialysis is a life-sustaining treatment for patients who have advanced kidney disease. Dialysis is a kidney replacement therapy, replacing some functions of the kidneys when they fail. It prevents life-threatening complications from the buildup of fluid, electrolytes, and the waste products of metabolism including urea, creatinine, and acid, that would normally be prevented through excretion from the kidneys.

WHAT IS HAEMODIALYSIS?

Haemodialysis is a form of dialysis that performs the functions of dialysis directly via the bloodstream. It is an extracorporeal therapy, meaning the procedure is performed outside of the body. A simple summation of haemodialysis is that it removes the blood from the body to perform the dialysis process and then returns the blood to the body.

WHAT DOES HAEMODIALYSIS DO?

Haemodialysis does not replace all the functions of the kidneys but prevents the life-threatening complications of kidney failure. There are some important considerations to this therapy:

- *Fluid removal needs to be accurate and safe.* At the end of haemodialysis, the patient needs to be euvolaemic, so not dehydrated and not overloaded, with minimal side effects for patients.
- *Electrolyte removal needs to be balanced to ensure the therapy leaves behind exactly what the body needs without leaving an excess or deficit.* This involves:
 - removing the correct amount of the correct electrolytes, e.g. potassium;
 - leaving behind the correct amount of electrolytes;
 - ensuring that other useful molecules in the body, such as glucose and medications, are not removed.
- *Removal of the waste products of metabolism needs to be maximised, whilst minimising complications from rapid removal of these waste products.* The waste products that haemodialysis normally focusses on removing are urea and creatinine. However, other waste products may also be removed via haemodialysis, some of which are not even known. These can include beta-2- microglobulin, cytokines, and uraemic toxins (Kirsch et al. 2016; Santoro and Guadagni 2010).
- *The metabolic acidosis that builds up from kidney disease is easily corrected.* This is completed in two

ways – administration of bicarbonate to buffer the blood pH and removal of excess acid.

When you start to examine what haemodialysis does and how it does this, you realise that the kidneys perform a phenomenal role in maintaining homeostasis in the body. Replicating this in an artificial therapy and ensuring individual conditions are maintained within a body is challenging.

To add to this challenge, haemodialysis is an intermittent therapy, normally undertaken three times a week, although current trends aim to increase this frequency. Therefore, haemodialysis is not undertaken simply to maintain the status quo but also correct imbalances that have accumulated in between haemodialysis sessions. Haemodialysis provides rapid corrections of the buildup of fluid, electrolytes, and waste products of metabolism and acid, which can also be challenging for the body to tolerate.

A combination of all these considerations makes haemodialysis a complex therapy to perform with potentially damaging effects on the body. Throughout this chapter this complexity will be explored, alongside how to optimise the therapy to minimise adverse effects and maximise outcomes for patients.

WHAT IS NEEDED TO PERFORM HAEMODIALYSIS SAFELY?

To perform haemodialysis, the most essential components are the dialyser and dialysate fluid. These are the elements that perform the dialysis process, providing the medium and conditions to remove the waste and excess products normally removed by the kidneys.

The *dialyser* uses a membrane to separate two compartments – one for the blood and one for the dialysate fluid. Current dialysers use a 'hollow fibre' approach where the membrane is structured into tubes. The blood flows through the middle of the tubes and the dialysate fluid flows in the space around the tubes (Figure 7.1). The blood and dialysis fluid flow in opposite directions.

Dialysate *fluid* is constructed to have the right components to draw excess electrolytes, waste products, and excess fluid out of the blood, across the membrane, and into the dialysate fluid. This dialysate fluid containing removed products, then exits the dialyser and is disposed of via the waste system and replaced with fresh dialysate fluid (Figure 7.2). The dialyser and dialysate fluid are individualised according to patient need. See 'Haemodialysis Prescription' section below.

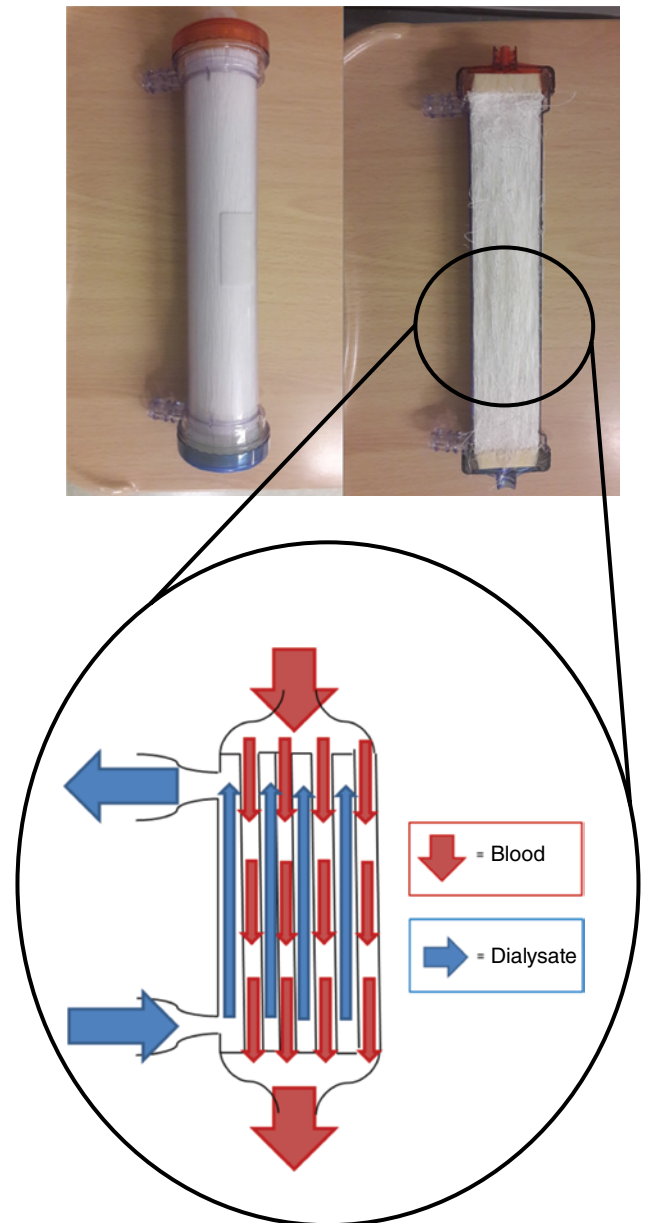


FIGURE 7.1 Image of a dialyser.

The *extracorporeal circuit* is a circuit of plastic tubes that runs to and from the dialyser. It incorporates many of the elements used to keep the dialysis process safe. The extracorporeal circuit includes:

- anticoagulation to prevent clotting in the extracorporeal circuit;
- pressure monitoring for both the circuit and vascular access;

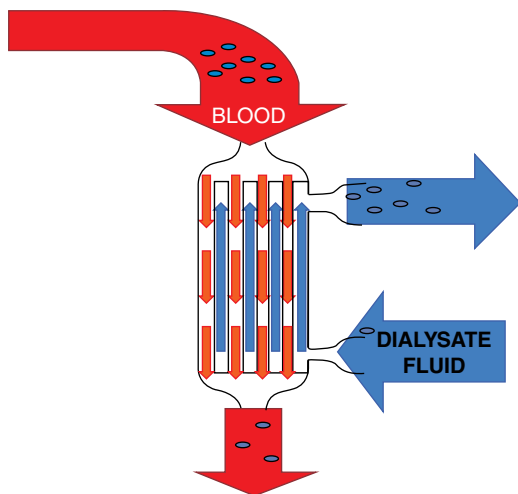


FIGURE 7.2 How the dialyser works.

- bubble traps to prevent air entering the patient;
- saline infusion that can administered in an emergency;
- monitoring functions for the machine and patient.

Correct handling of the extracorporeal circuit is essential to:

- Prevent contamination from bacteria, leading to infections in haemodialysis patients.
- Ensure air is not administered into the patient's circulation, causing an air embolism. Priming, secure connections, and clamping of lines is essential to prevent air entering the circuit at any point.
- Ensure red blood cells are not damaged through excess pressure, leading to haemolysis.

HAEMODIALYSIS MACHINERY

The haemodialysis machine provides the structure for the extracorporeal circuit to be mounted on (Figure 7.3). The machine provides three essential functions:

1. Creation and monitoring of the dialysate fluid. Dialysate fluid is created in a circuit within the machine, often known as the dialysate pathway. Sensors and pumps within this dialysate pathway ensure the dialysate fluid is of the correct composition. The dialysate pathway also removes waste dialysate.
2. Monitoring of the extracorporeal circuit and machine functions, to ensure the haemodialysis treatment is administered safely.



FIGURE 7.3 Image of an extracorporeal circuit and haemodialysis machine.

3. Provision of the haemodialysis prescription, providing a platform for this to be programmed, monitored, and translated into reality in the extracorporeal circuit.

Haemodialysis involves complex medical devices that bring about rapid correction of haemostasis through an extracorporeal circuit and vascular access. This is required for the correct dialysis prescription to be administered to the patient. The vascular access and extracorporeal circuit deliver the blood to the dialyser safely and then return the blood to the patient. The haemodialysis machine provides a monitoring function to ensure safe administration of the haemodialysis prescription.

However, patients' needs vary. Haemodialysis nurses need to assess what the patient needs from haemodialysis and their response to the prescribed treatment, allowing prompt adjustment as patients' needs change. Despite good assessment and advances in technology, complications still occur in haemodialysis, some frequently, due to the complexity of the treatment (Fielding et al. 2016a; Saha and Allon 2016). Haemodialysis nurses need to be able to

detect complications and know how to correct these, minimising harm to patients.

The whole process of maintaining a safe haemodialysis treatment and monitoring patients' response to the therapy requires skilled and knowledgeable haemodialysis nurses. Haemodialysis nurses need an understanding of:

- what the haemodialysis treatment is doing and how it is doing it;
- how to detect the patient's changing prescription needs and respond;
- what can go wrong in the treatment, how to prevent this, and how to respond when it occurs.

VASCULAR ACCESS

To remove and return the blood to the patient during haemodialysis requires access to the circulation. This is achieved through special vascular access, which normally comprises of two access points: one to remove the blood (often known as the arterial access) and one to return the blood (often known as the venous access).

Special vascular access is required as normal veins will not provide sustained support for haemodialysis. Vascular access provides the high blood flow rate (BFR) required for haemodialysis. It also needs to be robust, allowing repetitive use with the minimum number of complications.

There are three types of vascular access normally used for haemodialysis:

- arteriovenous fistula (AVF);
- arteriovenous graft (AVG);
- central venous catheter (CVC).

HOW DOES HAEMODIALYSIS WORK?

Haemodialysis works under a number of principles, which occur within the dialyser. These principles dictate how solutes and fluid are removed. The three main principles of haemodialysis are:

- diffusion
- ultrafiltration (UF)
- convection

The effects of other principles, such as concentration polarisation, are often considered in dialysis membrane technology – diffusion, UF, and convection are the principles of clinical significance.

DIFFUSION

Diffusion is a principle of nature that applies to solute removal in haemodialysis. It relates to the concentration difference between two solutions.

For diffusion to occur, the following circumstances are required:

- *A semipermeable membrane.* This is a permanent barrier with pores ('holes') that separates two solutions. The pores allow some molecules to move across but not all.
- *Two solutions containing molecules of different concentrations.* These two solutions are separated by the semi-permeable membrane. The molecules are called *solutes*, which are molecules dissolved in a fluid medium.

Diffusion states that when you have two solutions separated by a semi-permeable membrane, solutes will move from a high-concentration solution to a low-concentration solution (see Figure 7.4). What diffusion is attempting to do is equalise the concentration on either side of the membrane to create equilibrium.

Diffusion works through concentration differences, which are known as concentration gradients. The larger the concentration gradient, the more of the solute moves across the membrane or in the case of haemodialysis moves into the dialysate fluid. In haemodialysis, diffusion is used to manipulate what is removed and what is left behind. The dialysate fluid concentration is altered to

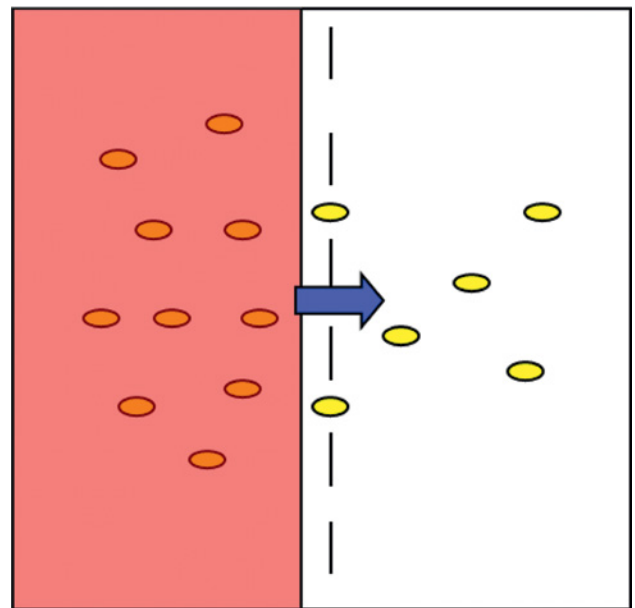


FIGURE 7.4 Diffusion.

diffuse out the molecules that need to be removed. For example, dialysate fluid contains no urea because as much urea as possible needs to be removed from the blood. However, whilst potassium also needs to be removed, the correct amount of potassium needs to remain in the blood. Therefore, some potassium is found in the dialysate fluid and the specific amount of potassium in the dialysate can be titrated to ensure that a safe level of potassium remains in the blood.

Diffusion is also affected by the properties of the membrane and the size of the molecules you want to remove. The size of the pores in the membrane, in comparison to the molecule size, can affect whether a molecule is able to move across the membrane. For example, the pores in the dialyser are made small enough not to allow red blood cells to move across.

Diffusion selects the type of solute removed based on these characteristics of dialysate concentration and membrane properties. However, sometimes molecules that need to be retained are lost – for example, medications. Whilst diffusion allows haemodialysis to be selective about what molecules it removes, it is still not perfect. Over a number of years, kidney research has worked towards manipulating the dialyser to assist in removal of what needs to be removed without removal of what should not (Clark and Gao 2002; Clark et al. 1999; Humes et al. 2006; Kirsch et al. 2016; Santoro and Guadagni 2010).

CONVECTION

Convection is a principle of physics and is often referred to in relation to heat movement. If the general principles of convection were explored in detail, it might be that it is explained in different ways from those explained in the context of dialysis. The following explanation will focus on how convection happens in haemodialysis.

Within the dialyser, convection occurs when fluid moves across the haemodialysis membrane. Convection is about the movement of solutes. A simple explanation of convection is that as the fluid moves across the membrane it pulls solutes with it (Figure 7.5). Hence why convection is often known in haemodialysis as *solute drag*.

SMALL, MIDDLE, AND LARGE MOLECULES

It is important to discuss molecule size in relation to haemodialysis. Small molecules are molecules like potassium, phosphate, and urea, which need to be removed by dialysis. Middle molecules are molecules such as beta-2-microglobulin, cytokines, and protein-bound uraemic toxins (Santoro and Guadagni 2010), which often need

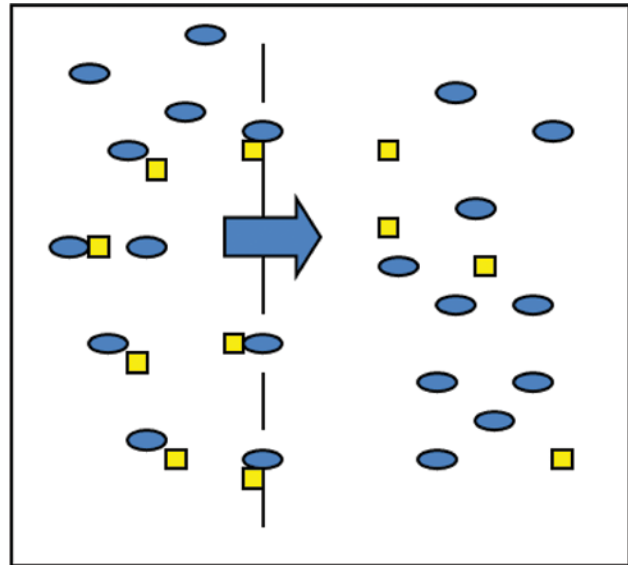


FIGURE 7.5 Diagram of convection.

to be removed. Larger molecules are molecules like blood cells and complex hormones. Usually these do not need to be removed by dialysis, although some uraemic toxins may fit into this category (Santoro and Guadagni 2010).

Diffusion is effective at removing small molecules, but not so effective at removing middle molecules. Convection is more effective at removing middle molecules (Santoro and Guadagni 2010). However, as little convection occurs in traditional low flux haemodialysis, it is considered to have little effect on solute removal. Haemodiafiltration (HDF) produces more convection as the fluid exchange promotes fluid movement across the membrane. However, high flux dialysers are also considered to promote convection through 'back-filtration' (Santoro and Guadagni 2010).

Research into dialysers and maximising the removal of the correct molecules continues. Recent studies have started to demonstrate how adsorption properties of membrane materials could assist in removal of other 'large molecule' uraemic toxins (Aucella et al. 2013; Kirsch et al. 2016; Santoro and Guadagni 2010).

ULTRAFILTRATION

Diffusion describes the process of molecule removal, and ultrafiltration (UF) describes the process of water removal. In haemodialysis, UF is driven by a pressure difference. UF creates a pressure difference or pressure gradient across the dialyser membrane. It achieves this by creating a negative pressure in the dialysate fluid that 'sucks' fluid across.

This is driven by pumps in the dialysate pathway, with the 'out' pump running faster than the 'in' pump and drawing water across the membrane and into the dialysate fluid (as shown in Figure 7.6).

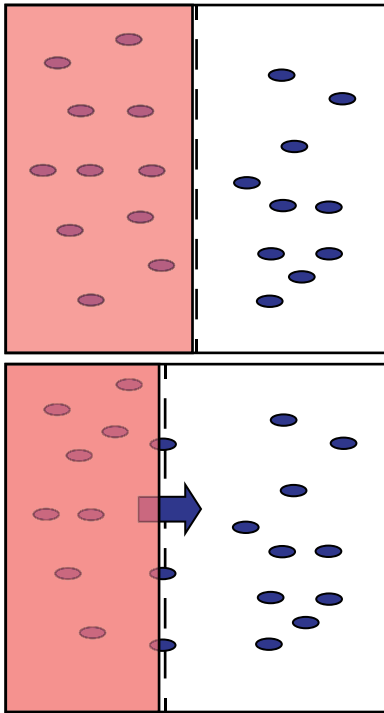


FIGURE 7.6 Creation of ultrafiltration (UF) in the dialysate circuit.

Current haemodialysis machines are volumetric, which means that the required fluid removal can be programmed into the machine and the machine will titrate the dialysate fluid pumps to remove the correct amount of fluid in a linear manner.

SUMMARY OF THE PRINCIPLES OF HAEMODIALYSIS

Whilst the three principles of haemodialysis are simple to describe, applying them to the practical removal of solutes and fluids in the dialyser to ensure the correct things are removed from the blood is complex. However, haemodialysis nurses should persevere to achieve understanding of this. These principles and their understanding allow the haemodialysis treatment to be tailored to individual need. The principles of haemodialysis are often described using a 'cup of tea' analogy. Whilst not physically accurate, this can allow nurses to visualise and understand these principles. This is outlined in Box 7.1.

MORTALITY AND HAEMODIALYSIS

Whilst improvements in hemodialysis are improving outcomes, patients undergoing dialysis continue to have a higher mortality rate than patients of a similar age who are not dialysing (UK Renal Registry, 2023). 'Kidney Health: Delivering Excellence' (Loud and Gallagher 2013) highlighted the need to continue to improve kidney services, ensuring all patients undergoing dialysis receive

BOX 7.1

THE 'NOT VERY ACCURATE' CUP OF TEA ANALOGY TO DESCRIBE THE PRINCIPLES OF HAEMODIALYSIS

Step 1 – Diffusion

When making a cup of tea, hot water is poured over the tea bag in the mug. As the tea bag then sits in the water, the water gradually turns brown as the tea 'diffuses' out of the tea bag and into the water.

- The tea bag is a membrane separating the water and the tea.
- There is no tea in the water and lots of tea in the tea bag.
- The tea molecule is small enough to move through the membrane of the tea bag.
- Tea moves out of the tea bag and into the water.
- Tea leaves are too large to move through the membrane so stay inside the tea bag.

Step 2 – Ultrafiltration

Once the tea is brewed, a spoon is used to squeeze the water out of the tea bag before it is removed. This squeezing motion, whilst a crude form of UF, uses pressure to remove water from the tea bag as UF would. In reality, the dialyser is not able to squeeze the blood, so negative pressure is used to 'suck' fluid out of the blood.

Step 3 – Convection

Milk is added to the tea and a spoon is used to distribute the milk evenly through the tea. The stirring motion moves the water molecules, which then drag the milk molecules with it.

NB: This analogy should not be taken as accurate or correct. However, it allows a demonstration of how diffusion, UF, and convection could work.

optimal care. Dialysis is a challenging therapy, associated with many complications and lifestyle changes for patients (Loud and Gallagher 2013). The UK Renal Research Strategy highlights one important area of focus is improving outcomes for patients on dialysis (Karet Frankl et al. 2016).

As well as quality improvement and research initiatives, haemodialysis nurses can ensure patients receive the best haemodialysis treatment that current evidence dictates. One way to achieve this is to tailor the haemodialysis prescription to patient's individual needs. This requires continuous and on-going monitoring and assessment of the effect of this prescription on the individual patient – a key role of nurses.

HAEMODIALYSIS PRESCRIPTION

The haemodialysis prescription includes various aspects that can be tailored to individual patient needs. Different aspects of the haemodialysis treatment can vary, which is normally dictated by availability of different equipment; the ability of the haemodialysis machine to alter parameters; the results of blood tests; patient symptoms and stability during and after haemodialysis; and patient choice.

Aspects that are normally altered come under the general areas:

- the type of dialysis, often known as modality;
- the dialysate fluid;
- the dialyser;
- aspects that affect the Kt/V and urea reduction ratio (URR);
- fluid removal;
- anticoagulation.

DIALYSIS MODALITY

Dialysis modality includes peritoneal dialysis or haemodialysis, but also the different types of haemodialysis such as whether the therapy is being undertaken at home. This section is going to explore the different modalities that come under the definition of haemodialysis, such as the frequency and length of haemodialysis treatments, use of HDF, and the location of the haemodialysis treatment.

The standard minimum haemodialysis modality currently is considered thrice weekly in-centre haemodialysis, with each treatment as a minimum of 4 hours using a high-flux dialyser.

One challenge of haemodialysis is the intermittent nature of the treatment, which leads to two significant issues:

- The correction of fluid, electrolytes, and acidosis alongside the removal of waste products of metabolism needs to be performed rapidly. This rapid removal can be difficult to tolerate.
- Fluid, electrolytes, and waste products of metabolism start to build up within the body once the haemodialysis session is completed. The time between haemodialysis sessions (sometimes 3 days) causes some of the long-term complications that haemodialysis patients experience.

This intermittent therapy causes peaks and troughs in the body. Removal of waste products occurs rapidly in haemodialysis, but then accumulates in between haemodialysis sessions. For example, glucose removal in haemodialysis can make diabetes management challenging (Allen and Fielding 2011; Frankel et al. n.d.; JBDS-IP 2016). Figure 7.7 demonstrates this peak and trough effect.

Outcomes from the DOPPS (Dialysis Outcomes and Practice Patterns Study) indicate that three times a week, 4 hours, haemodialysis does not lead to the best outcomes for patients, despite it being the main modality used in the UK and worldwide (Fotheringham et al. 2019; Zhang et al. 2012), with current UK guidelines recommending a more nuanced approach to schedules, considering individual patient priorities, balancing longevity against quality of life and residual renal function (Ashby et al. 2019).

HAEMODIAFILTRATION

HDF is one modality that may lead to better outcomes compared with standard haemodialysis (NICE 2018). The difference between haemodialysis and HDF is that HDF incorporates a fluid exchange. This is where 'extra' fluid is removed in the dialyser via UF. This 'extra' fluid is in excess

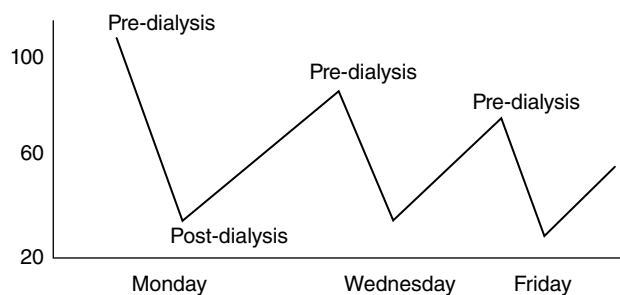


FIGURE 7.7 Peak and trough effect of haemodialysis.

of the programmed fluid loss required from each patient. As 'extra' fluid is removed, this also has to be replaced. This occurs through an infusion into the circuit. This removal and replacement of 'extra' fluid is the fluid exchange. The advantage of the fluid exchange is the 'extra' fluid removal, which leads to 'extra' fluid moving across the membrane in the dialysis. This triggers more convection in the treatment. HDF is often referred to as a 'convective' therapy.

Previously, large bags of infusate were attached to the circuit to replace the 'extra' fluid removed, but current technology allows dialysate to be used as the infusate. This is often known as on-line HDF. This advancement in technology to on-line HDF has allowed an increase in the volume of exchanges performed. HDF machines have an essential role in balancing the 'extra' fluid removed with that replaced, to ensure the fluid exchange does not interfere with the patient's fluid balance.

HDF was originally designed as combination of haemodialysis and haemofiltration, which at the time, was associated with removal of large as well as small molecules (Cioni et al. 1984; Kohlne et al. 1979). Early studies demonstrate the rationale for HDF was to promote better removal of middle molecules and large molecules like beta-2-microglobulin and uraemic toxins (Cioni et al. 1984; Henderson et al. 1975; Kohlne et al. 1979). Following an initial study, Henderson et al. (1975) stated that the solute clearance pattern of HDF was very similar to the human kidney, and this is in sharp contrast to standard haemodialysis.

However, with the advent of high flux haemodialysis, more recent studies have struggled to identify the benefits of HDF on patient outcomes. The DOPPS examined outcomes for patients on HDF (Canaud et al. 2006). They identified that HDF with high exchange volumes was associated with lower mortality than both high flux and low flux haemodialysis (Canaud et al. 2006). However, the improvement in mortality was not significant with low volume of exchanges with HDF (Canaud et al. 2006). However, randomised control trials have struggled to identify a benefit to HDF over high flux haemodialysis (Smith et al. 2017; Vilar et al. 2009). Nistor et al. (2015) updated a Cochrane review and were unable to identify a benefit to convective therapies, due to the limitation and bias in current studies. The benefit of HDF may lie in the high volume of the fluid exchange, which is not always achieved (Chapdelaine et al. 2014), with the CONVINCe study demonstrating that if high convective volumes are achieved with HDF, then it improves mortality over 6-month period, when compared to high flux hemodialysis (Blankstijn et al. 2023). The debate currently continues with the H4RT trial currently in progress in the UK, comparing high

volume HDF to high flux hemodialysis, with results that will indicate the benefits of HDF over a longer follow up period (Caskey et al. 2022).

MORE FREQUENT AND LONGER HAEMODIALYSIS

Another way to reduce the intermittent effect of haemodialysis is to perform haemodialysis more frequently. The rationale is that fluid, waste products of metabolism, and electrolytes have less opportunity to build up in between sessions and more frequent sessions can thus be shorter, as there is less abnormality to correct. As the body system is being corrected less and more frequently, leading to fewer 'peaks and troughs', it can be hypothesised that this leads to better outcomes for patients (Twardowski and Misra 2010).

This rationale has recently been proven in research studies. In particular, the Frequent Hemodialysis Network (FHN) in the United States has performed studies into frequent haemodialysis versus normal thrice weekly haemodialysis. They have identified that six times weekly haemodialysis in-centre leads to:

- reduced mortality, improved heart function, and improved blood pressure and phosphate control (The FHN Trial Group 2010).
- reduced extracellular water (Kaysen et al. 2012), indicating better fluid status control.
- improved self-reported physical health and function (Hall et al. 2012).
- improved mental health (Unruh et al. 2013).

Jefferies et al. (2011) also identified that more frequent haemodialysis was associated with less cardiac injury, possibly as this is related with lower ultrafiltration rates (UFRs).

Studies have also examined the adverse effects of more frequent haemodialysis. Notably, albumin loss and nutritional status do not appear to be affected by more frequent haemodialysis (Kaysen et al. 2012; The FHN Trial Group 2010). Studies examining vascular access complications have conflicting results. The FHN Trial group (2010; Suri et al. 2013) identified more vascular access complications with more frequent haemodialysis; however, Achinger et al. (2013) performed a longer study and identified no effect of more frequent haemodialysis on vascular access outcomes.

More frequent haemodialysis appears to be associated with improved outcomes. There is agreement within the kidney community that this promotes more normal

function for the body. However, current provision of haemodialysis for the majority of patients remains at thrice weekly haemodialysis. Whether this is driven by patient choice and culture, or the availability of haemodialysis capacity is unknown.

Longer haemodialysis is also considered to improve outcomes for patients. This was first demonstrated in Tassin, France, where they performed haemodialysis for 8 hours, thrice weekly, for all their patients. They consequently improved survival (Innes et al. 1999), probably through improved blood pressure control without the use of anti-hypertensives (Charra et al. 1992; Innes et al. 1999). The DOPPS also identified that longer haemodialysis treatments, with lower UFRs, led to reduced mortality (Saran et al. 2006). However, since then the use of this regime of haemodialysis has not translated into practice, possibly due to the emergence of nocturnal haemodialysis and poor patient tolerance of longer treatment time. A recent systematic review found no benefit to extended hours dialysis, although the studies had a high risk of bias, thus a further large randomized controlled trial with longer follow-up is needed to establish its benefits (Hull et al. 2020).

NOCTURNAL DIALYSIS

Nocturnal haemodialysis combines the benefits of frequent and longer, slower haemodialysis. Nocturnal dialysis normally involves dialysing for 6–8 hours a night, using a slower dialysate flow rate and BFR to slow the dialysis process. Patients normally dialyse for up to six nights a week, adding the benefit of more frequent haemodialysis.

The FHN performed a trial examining the effect of nocturnal six times a week haemodialysis compared with three times a week haemodialysis. However, they were unable to identify any benefit to nocturnal haemodialysis, but identified this could be due to small patient numbers (Rocco et al. 2011). However, other studies have found a benefit to nocturnal haemodialysis, including:

- improved survival (Bridge and Holt 2015; Lockridge and Kjellstrand 2011);
- improved anaemia control (Poon et al. 2015; Tang et al. 2011);
- improved cardiac markers (Thomson et al. 2014) including decreased left ventricular mass (Friesen et al. 2015; Tang et al. 2011) and reduced arterial stiffness (Bridge and Holt 2015; Demirci et al. 2012);
- improved phosphate control (Tang et al. 2011);

- improved blood pressure control (Tang et al. 2011; Xi et al. 2011);
- improved clearance (Poon et al. 2015; Tang et al. 2011);
- improved quality of life (Tang et al. 2011; Xi et al. 2011).

The majority of these studies are observational, sometimes with small patient numbers, so no true comparison via a randomised trial has been performed. Initially there was concern about the burden of this treatment regime. However, studies have indicated that nocturnal haemodialysis could be associated with less burden of treatment and improved mental health, especially when used in the correct patient and family context (Rioux et al. 2012; Xi et al. 2011). The Nightlife study is still in progress within the UK to assess the benefits of nocturnal versus daytime hemodialysis (Hull et al. 2023).

HOME HAEMODIALYSIS

Since NICE recommendations (2002) on home haemodialysis were published, there has been an emphasis on improving home haemodialysis rates. NICE (2002) recommended that all patients who are suitable should be offered home haemodialysis as a modality of choice. Home haemodialysis improves clinical outcomes, in a similar manner to those discussed with more frequent and longer and nocturnal haemodialysis. NICE (2002) also identified home haemodialysis as economically efficient when compared with in-centre haemodialysis. The NICE (2002) recommendations are still considered relevant despite their age.

One main benefit of home haemodialysis is the flexibility of the treatment regime. This allows options of longer, more frequent haemodialysis, including nocturnal haemodialysis. Currently, 4 hours of haemodialysis thrice weekly remains the main in-centre modality, with the home setting use for other modality choices.

Home haemodialysis can have advantages for patients feeling they have regained control of their life and decisions about their health, as well as developing a 'healthy' self-identity rather than taking on the sick role (Walker et al. 2015; Xi et al. 2011). However, home haemodialysis can also cause patients and carers concern including feelings of vulnerability, especially in relation to potential complications; social isolation and disconnection from medical personnel, plus there is a potential burden on carers to support the home treatment (Walker et al. 2015).

Many initiatives are in development to increase the number of patients accessing home therapies and home haemodialysis. DAYLife a national project to improve the uptake of home therapies (KQuIP 2024). SHARE-HD is a

quality improvement project designed to encourage patients to become more involved in their care and also to encourage more independent haemodialysis (Fotheringham et al. 2021; Wilkie and Barnes, 2019).

There are numerous ways of performing haemodialysis that can be individualised to patients' clinical, psychological, and social needs. Whilst certain modalities have benefits, these benefits are only proven for those patients where the modality works for them. In reality, modality choice needs to be a balance between what is proven to have the best clinical outcomes, considered alongside what will suit that individual patient's lifestyle and concerns.

THE DIALYSATE

The dialysate comprises three components (Figure 7.8):

1. electrolyte solution, often call acetate or 'acid';
2. sodium bicarbonate;
3. ultra-pure water.

In online HDF treatments, the dialysate fluid is also used as the replacement fluid for the fluid exchange (Figure 7.9).

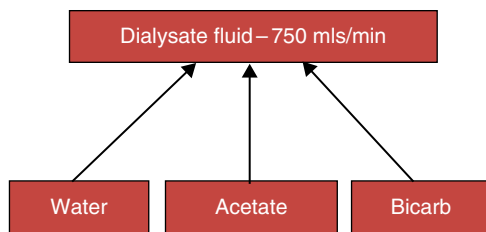


FIGURE 7.8 Composition of the dialysate fluid.

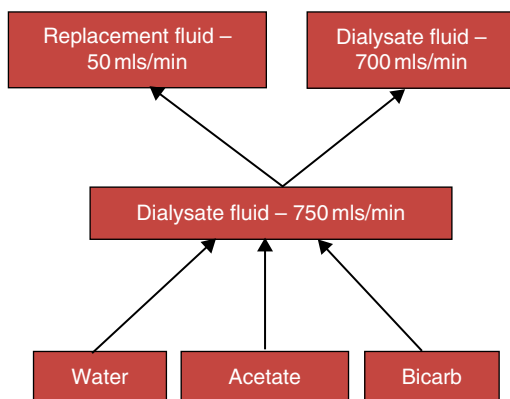


FIGURE 7.9 Dialysate use in haemodiafiltration (HDF).

Therefore, the dialysate is infused directly into the patient and contains all the constituents of normal dialysate. For this reason, it becomes even more important in HDF that the dialysate fluid is of the correct composition and does not contain undesired elements.

The three components of the dialysate will now be examined, alongside how they may vary during individual haemodialysis prescription.

Acetate

The main electrolytes included in normal acetate are:

- **Potassium.** Acetate solutions can vary from 1 to 4 mmol l⁻¹. This is usually prescribed by the nephrologist and determined from monthly blood potassium levels. However, the latest results from the DOPPS indicate that altering the potassium in the dialysate has less effect on pre-dialysis potassium levels than other interventions to manage potassium (Karaboyas et al. 2017).
- **Calcium.** Dialysate concentration can vary from 1 to 1.75 mmol l⁻¹. Varying the calcium concentrations in dialysate is uncommon but may be used when deranged serum phosphate levels alter the control of serum calcium. Higher calcium dialysate concentrations (1.5 or 1.75 mmol l⁻¹) may be used post-parathyroidectomy, when patients often initially have low serum calcium levels, until physiological control is stabilised.
- **Glucose.** This is normally set at 90 mg dl⁻¹ or 1 g l⁻¹ depending on the make of acetate. Low levels of glucose in the dialysate can lead to hypoglycaemia (Burmeister et al. 2012; JBDS-IP 2016). Use of 1 g l⁻¹ glucose in dialysate is now recommended for patients with and without diabetes to prevent hypoglycaemia balanced with inflammation created by glucose in the dialysate (Allen and Fielding 2011).

Other electrolytes in the acetate include magnesium, chloride, acetic acid and sodium. These are rarely altered within the clinical environment. Whilst research has examined altering of these levels, especially magnesium, or addition of vitamins to the dialysate to prevent vitamin loss, none of this research has changed clinical practice.

Bicarbonate and sodium

Sodium bicarbonate is another component of dialysis fluid, which supplies both bicarbonate and sodium to the dialysate. Bicarbonate normally comes in one concentration, but haemodialysis machines can then

vary the levels of sodium and bicarbonate through the prescription programmed into the machine. Bicarbonate levels are set physiologically and normally within individual centres there is little variation in patient prescriptions. As a general rule, the bicarbonate level in the dialysate is set to correct the metabolic acidosis that develops in between haemodialysis sessions. Patients normally arrive with low bicarbonate levels; bicarbonate diffuses into the blood during treatment and then patients leave with higher bicarbonate levels.

Sodium levels in the dialysate are an area of debate. Sodium has previously been used in high levels in the dialysate to make fluid removal more tolerable for patients (Davenport 2009a). This occurred via 'sodium profiling'. However, this often led to high sodium blood levels which increased the patient's blood pressure and made them thirsty, increasing inter-dialytic weight gains (IDWG) (McCausland and Waiker 2014). Current thinking recommends setting the sodium dialysate close to the individual patient's normal levels and aim for this to be lower rather than higher. A Cochrane review found lower sodium levels in the dialysate reduced IDWG and possibly reduced the amount of antihypertensive medication patient required (Dunlop et al. 2019). However, lower sodium levels in dialysate possibly increased the frequency of intradialytic hypotension events and intradialytic cramps (Dunlop et al. 2019). They concluded further evidence was still required (Dunlop et al. 2019).

Ultra-pure water

To ensure the acetate and sodium bicarbonate are mixed to the correct concentrations, ultra-pure water is used to dilute these concentrates. This allows efficiency of the volume of concentrate attached to the haemodialysis machine. As mentioned earlier, the process of diffusion in the dialyser is not selective. Therefore, anything that is in the water in the dialysate that is not present in the patient's blood, or present in lower concentrations, will diffuse into the blood. Coupled with the volume of water exposed to the blood in a single haemodialysis treatment (90–120 l), this allows contaminants to enter the blood in large volumes.

Normal drinking water contains copper, fluoride, aluminium, calcium, magnesium, bacteria, and endotoxins. If present in the dialysate water, these could all diffuse into the bloodstream causing ill health in patients. In particular, haemolysis can occur from bleach contamination of water dialysate (Davenport 2006; Rylance 2014). The UK Renal Association has produced their own guidelines on water quality standards for haemodialysis in the UK (Hoenich et al. 2016).

THE DIALYSER

The dialyser can vary in three ways:

1. *Size of the membrane.* This is expressed in surface area. It works through a very simple principle – the larger the surface area of the dialyser, the more diffusion can occur in the dialyser, which then allows more solutes to be removed. Often the level of clearance required, indicated by the Kt/V , dictates the size of the dialyser.
2. *Flux of the membrane.* Dialysers can either be low flux or high flux. This relates to the size of the pores in the membrane. High flux dialysers have larger pores and are designed to allow middle molecules as well as small molecules to be removed. Low flux dialysers only allow removal of small molecules. High flux dialysers are now the recommended standard for haemodialysis, to allow this middle molecule removal (Ashby et al. 2019). High flux dialysers are also required for HDF, to allow the volume of fluid to pass over the membrane that is required for the fluid exchange.
3. *Biocompatibility.* Membrane biocompatibility is considered the ability of the membrane to minimise the complement activation caused by the artificial nature of the membrane (Clark et al. 1999). In simpler terms, it is the ability of the membrane to minimise the reaction to the artificial membrane. In the last few decades, work has been focussed on reducing complement activation from the membrane whilst also reducing thrombogenicity (ability to promote clotting), as described by Clark et al. (1999). Current practice has moved to the use of synthetic membranes including AN69 ST, polysulfone, and polyamide membranes. The majority of membranes have a similar level of biocompatibility, although if reaction to one membrane is suspected, then movement to another membrane is recommended.

HAEMODIALYSIS CLEARANCE

Many aspects of the haemodialysis prescription can be altered. One focus of the haemodialysis prescription is to achieve the level of clearance of solutes that the individual requires. This was previously known as adequacy, but adequacy has become a more inclusive term to encompass all aspects of haemodialysis. Now the term *adequacy* has been replaced by the term clearance and describes how much effective haemodialysis is achieved. This section will examine how to best measure the clearance, and how to control or maximise this clearance to achieve the best outcomes for patients.

Kt/V and Urea reduction ratio

Haemodialysis clearance can be measured in two ways – Kt/V or URR. Both methods are currently in use within the UK and both have advantages and disadvantages. Both Kt/V and URR measure urea clearance during a haemodialysis treatment but contextualise and express this in different ways.

Kt/V is an equation. It produces a ratio to describe urea clearance in a haemodialysis treatment. The equation is expressed as follows:

$$\frac{\text{Urea Clearance (K)} \left(\text{in mls/min} \right) \times \text{Time (t)} \left(\text{in mins} \right)}{\text{Distribution volume (V)} \left(\text{mls} \right)}$$

The distribution volume is the volume of body water in the body and is included in Kt/V to allow for the fact that urea is stored in all water within the body and not just within the blood.

URR measures the percentage reduction of urea during a haemodialysis treatment. Kt/V and URR both gained significance in the early 1990s, when large multi-centre studies within the US demonstrated that achieving a significant level of Kt/V or URR led to improved survival for patients (Held et al. 1996; Parker et al. 1994). UK Renal Association guidelines (Ashby et al. 2019) recommend that patients dialysing thrice weekly should have a Kt/V greater than 1.2. These levels have been associated with the best patient outcomes, although there is some debate whether achieving higher clearance levels than this will lead to better outcomes.

Measurement of URR and Kt/V

Kt/V or URR are normally measured by taking a urea level before and after dialysis, thus identifying how much urea is removed during treatment. Whilst this seems a simple procedure, the post-dialysis sample requires consideration. Following haemodialysis, solute levels within the blood experience a phenomenon known as *rebound*, which is described in Box 7.2. This means the urea level post-haemodialysis is falsely low and will overestimate the URR or Kt/V .

To compensate for urea rebound various post-haemodialysis sampling techniques have been developed. These involve either slowing the blood pump speed prior to disconnection from haemodialysis or stopping the dialysate flow before taking the post-dialysis sample (Mactier et al. 2011). Individual unit policy can vary and there is no one single recommended method for taking the post-dialysis blood sample.

Kt/V can also be measured through an online clearance monitor present on the majority haemodialysis machines.

BOX 7.2

UREA REBOUND

During haemodialysis, solutes are removed from the blood. However, solutes are also stored outside of blood, in water in other compartments in the body (i.e. interstitial fluid, intracellular fluid).

In haemodialysis:

- Urea is removed from the blood during haemodialysis.
- The urea level in the blood is then lower than the urea level in the interstitial and intracellular fluids.
- Diffusion pulls urea from the interstitial and intracellular fluid into the blood.

Following haemodialysis:

- The urea level in the blood is lower than the urea level in the interstitial and intracellular fluid.
- Therefore, urea is pulled from these fluids and into the blood for 1–2 hours after haemodialysis until the level is equal in all three fluids.

This means the blood urea level directly after haemodialysis is falsely low and will 'rebound' up in the first two hours after haemodialysis.

These come in a variety of forms but have advantages, including:

- *Provision of a real-time measurement of Kt/V.* This makes it easier to relate actions in the treatment to the Kt/V result. For example, the effect of increasing BFRs during treatment can be directly observed, providing valuable feedback to the nursing staff running the haemodialysis session.
- *Provision of a reading at every haemodialysis session.* McIntyre et al. (2003) found that Kt/V readings vary from adequate to inadequate over a 4-week period in 55% of patients. This indicates that a monthly assessment of Kt/V via blood samples does not provide a true reflection of the haemodialysis dose the patient has received over the month.

IMPROVING CLEARANCE

Regardless of whether Kt/V or URR is measured, the general theme is that haemodialysis clearance needs to be optimised for individual patients.

Within a single haemodialysis treatment there are a number of factors that can affect the clearance and be altered to improve clearance:

- *Dialyser size* Increasing the dialyser size can serve to increase the clearance.
- *Blood flow rate* (BFR) affects clearance through a very simple principle that the faster the BFR, the more blood is processed in the haemodialysis treatment.

This means more blood is exposed to the dialyser membrane in the treatment time and clearance improves. BFR is considered the factor that can have the most effect on clearance. Lambie et al. (2004) found that higher BFR lead to a better clearance. Borzou et al.'s (2009) study demonstrates that a relatively small increase in BFR from 200 to 250 ml min⁻¹ had a significant effect on improving both URR and Kt/V. There has also been a direct link between BFR and mortality, where BFRs lower than 250 ml min⁻¹ have been associated with higher mortality rates (Chang et al. 2016).

However, the relationship between BFR and clearance is not linear, with the benefits of increasing BFR reducing as higher BFR are achieved. This could be related to a number of hypotheses:

- *The blood requires time in the dialyser for diffusion.* The faster the blood moves through the dialyser, the less time is available for diffusion, so there may be a point where higher BFR does not lead to more diffusion.
- *Higher flow rates are associated with higher arterial pressures.* Higher flow rates and arterial pressures can increase vascular access recirculation, ultimately reducing the clearance.

There is often an optimal BFR that obtains the best clearance. Within the UK, adequate BFRs can vary between 200 and 500 ml min⁻¹. However, there is significant variation in unit policy. Haemodialysis nurses can be reticent to increase BFRs due to concerns of pressure alarms and effect on patient stability which is often unfounded (Lambie et al. 2004). With the advent of online clearance monitors, it is now easy for haemodialysis nurses to assess the effect of changes in BFR on the clearance during the haemodialysis session. Haemodialysis nurses need to consider what is the best BFR for individual patients, that maximises clearance, rather than adhering to rigid policies:

- *Dialysate flow rate.* Dialysate flow rates can also be used to improve clearance. The higher the dialysate flow rate the better the clearance (Hauk et al. 2000). Currently haemodialysis machines can vary the dialysate flow rate from 300 to 800 ml min⁻¹. Higher dialysate flow rates can be used to improve clearance and lower dialysate flow rates used to slow clearance, for example in nocturnal haemodialysis.

- *Vascular access recirculation.* Zeraati et al. (2013) define vascular access recirculation as 'some of the dialysed blood leaving the dialyser through the venous needle, re-enters the dialyser through the arterial side'. This reduces clearance as previously dialysed blood enters the dialyser again. In reality, an element of recirculation happens in all haemodialysis treatments, but the aim is to minimise this. Vascular access recirculation is often expressed as a percentage of the total blood dialysed.

Factors that affect vascular access recirculation include:

- *Vascular access type.* Recirculation happens to a higher extent with CVC due to the proximity of arterial and venous lumens in the same vein.
- *Position of needles within AVF/AVG* (Zeraati et al. 2013). The arterial and venous needle should be at least 2 inches apart to minimise recirculation between the two needles.
- *Presence of venous stenosis.* This promotes back flow in the AVF/AVG increasing recirculation (Zeraati et al. 2013).
- *Inadequate flow in the AVF/AVG.* Flow is lower than the blood pump speed (Zeraati et al. 2013).

Many of these factors are related to vascular access function. Recognition of poor vascular access function can allow referral to improve this.

SINGLE-NEEDLE OR DOUBLE-NEEDLE DIALYSIS

Single-needle dialysis uses one point of access into the circulation for haemodialysis. This could be one needle or a single-lumen CVC. Consequently, double-needle dialysis is when two points of access are used either via two needles or a dual-lumen CVC. Single-needle dialysis will usually lead to poorer clearance than double-needle dialysis, for two reasons:

1. Vascular access recirculation is increased in single-needle dialysis, as only one lumen is used to return and remove the blood.
2. BFRs are lower due to the configuration of single-needle dialysis to minimise access recirculation.

Single-needle dialysis should only be used temporarily for haemodialysis treatments, as this does not provide adequate clearance for long-term treatments.

Clotting in the dialyser

Adequate anticoagulation of the dialyser is essential to maintain clearance throughout the haemodialysis treatment. Clots that form on the membrane of the dialyser serve to block diffusion. Therefore, the anticoagulation regime is essential to maintain the function of the dialyser through the treatment. Priming of the dialyser is also essential. Air pockets in the dialyser during haemodialysis promote clot formation on the membrane and reduce clearance. The priming process needs to ensure all air is removed from the dialyser prior to commencing haemodialysis.

KIDNEY NURSE'S ROLE IN MAINTAINING AN OPTIMAL HAEMODIALYSIS PRESCRIPTION

Elements of the haemodialysis prescription that will change over long periods of time and are often assessed monthly have been discussed in previous sections. The variations discussed so far are often made following assessment of U&E results and *Kt/V*. Changes to the prescription can then be made to the equipment used for haemodialysis and the prescription programmed into the machine. These elements are often managed by consultant nephrologists and/or senior haemodialysis nurses. The role of the junior haemodialysis nurse in this situation is to have awareness of what may need to change, refer to more senior colleagues for advice, and understand how to implement changes and why they may be necessary.

Many aspects of the haemodialysis prescription may change on a day-to-day basis. Due to more frequent variation, assessment and decisions to change these aspects are within the role of all haemodialysis nurses.

FLUID REMOVAL

Assessment of correct fluid removal for haemodialysis is an essential role of haemodialysis nursing staff. The amount of fluid removed during each haemodialysis session can fluctuate in between sessions, alongside how well patients tolerate the fluid removal. For each session, haemodialysis nurses need to determine how much fluid to remove and how to do this in a safe manner for the patient. The dry weight (also known as target weight or ideal weight) is normally used to determine the amount of fluid to remove.

Challenge of fluid removal

Most instability during haemodialysis is caused by fluid removal. Unless another cause is known, low blood pressure during haemodialysis (intra-dialytic

hypotension [IDH]) is normally attributed to poor tolerance of fluid removal and is the most frequent adverse event during haemodialysis (Davenport 2009a). An audit of adverse events during haemodialysis identified that hypotension was the most common adverse event during haemodialysis and accounted for 29.3% of all adverse events during haemodialysis treatments (Fielding et al. 2016a).

Ensuring stability during haemodialysis requires management of multiple aspects. IDH can be related to UFR, which is dictated by the amount of fluid to be removed, and the accuracy of the dry weight, which ensures the correct amount of fluid is removed (Davenport 2006). The patient needs to be monitored through treatment for signs of IDH and poor tolerance of fluid removal. IDH should always be treated promptly with reduction in UFR to minimum levels, saline bolus of 100–200 ml, and reclining the patient (Davenport 2009a).

Dry weight assessment

Fluid removal during haemodialysis is normally dictated by the dry weight. Patients' weight prior to haemodialysis treatments and how much they are over their dry weight indicates how much excess fluid is present, which needs to be removed. 1 g of body weight is equivalent to 1 ml of fluid (1 kg of body weight is equivalent to 1 l of fluid).

To ensure fluid removal programming is accurate, the dry weight needs to be accurate. The dry weight indicates the weight the patient should be at euvolaemia, without any excess fluid present and without any dehydration. However, dry weight can fluctuate as patients gain and lose body mass, through muscle and fat changes, so the dry weight requires frequent assessment. Indications that dry weight requires adjustment are summarised in Figure 7.10.

Dry weight assessment can be complex. Other comorbidities can affect the dry weight assessment, including cardiac disease which is common in patients with kidney disease. Symptoms during haemodialysis can also be caused by high UFR rather than a need to adjust dry weight. Haemodialysis nurses need to gain the skills of dry weight assessment and identify any changes in dry weight promptly, to prevent IDH from inaccurate fluid removal. In particular, nurses need to learn to consider all pertinent factors that can affect the assessment of dry weight, including the trends of change, rather than overly relying on assessment of one factor.

Accurate dry weight assessment is crucial for haemodialysis. IDH is frequent, but also harmful to patients' long-term outcomes. McIntyre (2010) describes how improving

Factor	Indication	Related Signs and Symptoms
Blood pressure	Low usually indicates need to increase dry weight	• Dizziness • Vomiting • Unresponsive / fainting • Instability on haemodialysis
	High indicates need to decrease dry weight	• Headache
Oedema	Ankle oedema or pulmonary oedema indicates need to decrease dry weight	• Ankle swelling with pitting oedema • Shortness of breath • Cough with white frothy sputum • Inability to lie flat
Appetite	Reduction indicates need to decrease dry weight	Patient reported change in appetite
	Increase indicates need to increase dry weight	
Changing fluid status	Decreasing fluid gains indicate need to decrease dry weight	Patient reports no change in fluid intake
	Increasing fluid gains indicate need to increase dry weight	
Cramps	Cramps indicate need to increase dry weight	Muscle cramps during haemodialysis in the absence of high ultrafiltration rates

FIGURE 7.10 Indicators that dry weight requires adjustment.

stability of haemodialysis reduces damage to the heart during haemodialysis. IDH also causes distressing symptoms, discomfort, and anxiety for patients. However, the effects of fluid overload also need to be limited. As patients are usually unable to excrete excess fluid, even if post-haemodialysis treatment euvolaemia is achieved, once the patient drinks or eats again they become fluid overloaded. This fluid stays in their system until the next haemodialysis treatment. Patients are often prone to left ventricular hypertrophy due to a number of reasons, one of which is the stress from fluid overload. Cardiac disease continues to be the leading cause of death in patients undergoing dialysis (UK Renal Registry, 2023). However, ensuring accurate dry weight will reduce the stress and damage caused to the heart during haemodialysis and in between haemodialysis sessions.

Technology may be developing to assist in the assessment of dry weight. Bioimpedance technology works using electrical currents to estimate the volume of extracellular water. This assessment indicates whether a patient is over- or underloaded with fluid and can estimate by how much. Initial studies have shown that bioimpedance measurements are objective and accurate in assessing dry weight (Moissl et al. 2013; Onofriescu et al. 2012; Wabel et al. 2009). Within the UK the BISTRO clinical trial is evaluating the use of bioimpedance to assess dry weight on a larger scale (Davies et al. 2017).

MANAGING FLUID LOSS

Prior to each haemodialysis session, the nurse needs to determine the correct fluid to remove from the patient. Whilst the dry weight can be used to determine what should be removed, the haemodialysis nurse also needs to assess whether the patient will tolerate the volume of fluid to be removed in the treatment time. Haemodialysis can only remove fluid from the blood, as not all fluid within the body is stored in the vascular space. Fluid is also stored in the cells (intracellular space) and around the cells (interstitial space) (Figure 7.11). As excess fluid builds in the body, fluid distributes between these three spaces. As fluid is removed from the vascular space, the blood becomes more concentrated and pulls fluid from the interstitial and intracellular spaces by osmosis. This process is known as *refilling* (Figure 7.12).

To be able to remove all the excess fluid from each compartment, refilling needs to occur (Davenport 2009a). The best way to describe this process in haemodialysis is to explore what happens in the three fluid compartments (see Figure 7.11).

Prior to haemodialysis, excess fluid equilibrates across all 3 fluid compartments. Once haemodialysis is commenced, fluid is removed from the vascular compartment reducing the volume in this compartment. As fluid is removed from the vascular space, this fluid

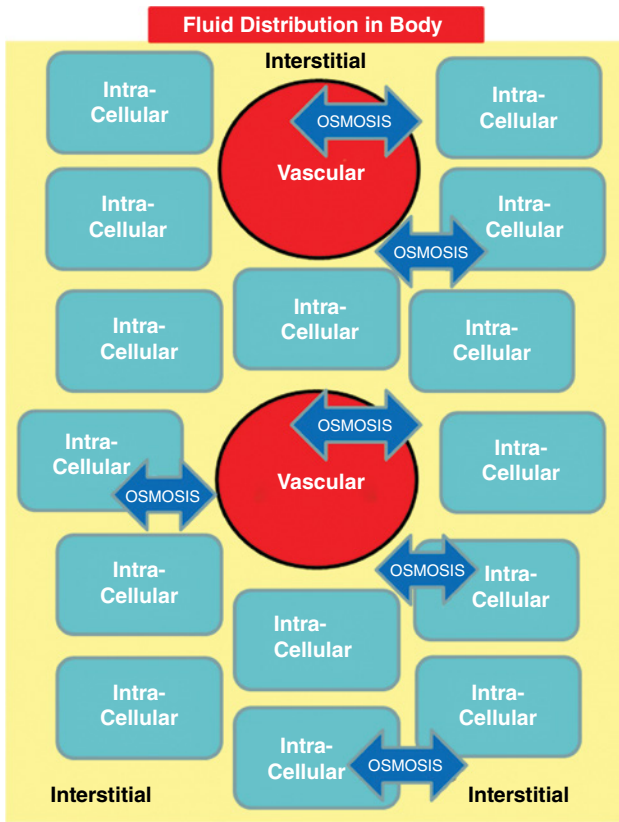


FIGURE 7.11 Fluid distribution in the body.

becomes more concentrated so draws fluid from the ICF and IF compartments. This reduces the volume in the ICF and IF compartments. At the end of haemodialysis, the excess fluid has been removed from all three compartments.

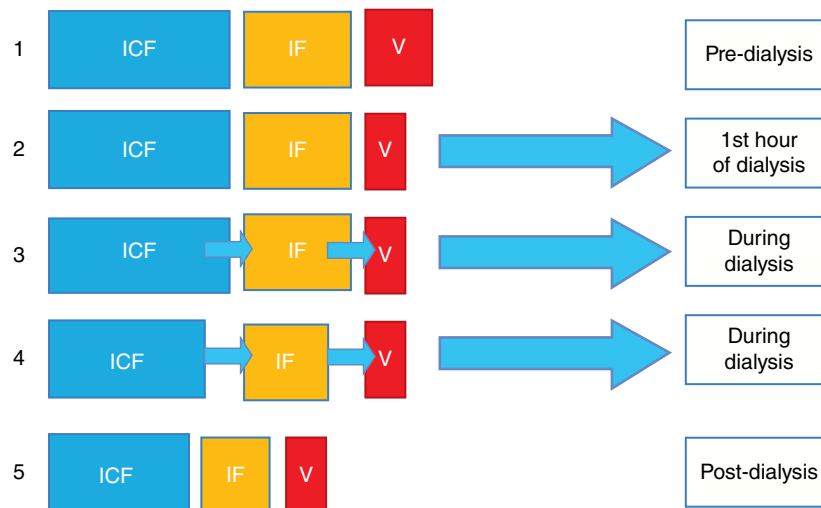


FIGURE 7.12 Refilling during haemodialysis.

In Figure 7.12, ICF represents the volume in the intracellular compartment, IF represents the volume in the interstitial compartment, and V represents the volume in the vascular compartment.

Ideally, this process should happen in a manner that ensures the volume in the vascular compartment is maintained, preventing IDH. When UFR exceeds the refilling rate, the volume in the vascular space reduces through treatment, making it harder to maintain the blood pressure (Figure 7.13). Post-haemodialysis the volume in the vascular compartment will return as refilling catches up with the fluid removal, but then each compartment has excess fluid present.

It is important to manage the UFR and refilling rate to maintain stability through haemodialysis (Davenport 2009a). Not only does this ensure stability through haemodialysis, but lower UFRs have been associated with reduced mortality (Saran et al. 2006) and less cardiac damage (Jefferies et al. 2011).

MANAGING THE UFR

A number of things can be done to help minimise the UFR:

- *Manage IDWG.* The less fluid the patient has to lose in the prescribed dialysis time, the lower the UFR will be. Patients are often advised on fluid allowances to manage IDWG. These allowances vary between 500 and 1000 ml in 24 hours, plus whatever their 24-hour normal urine output is. However, a low fluid allowance can be difficult for patients to adhere to, so advice about thirst management is critical.

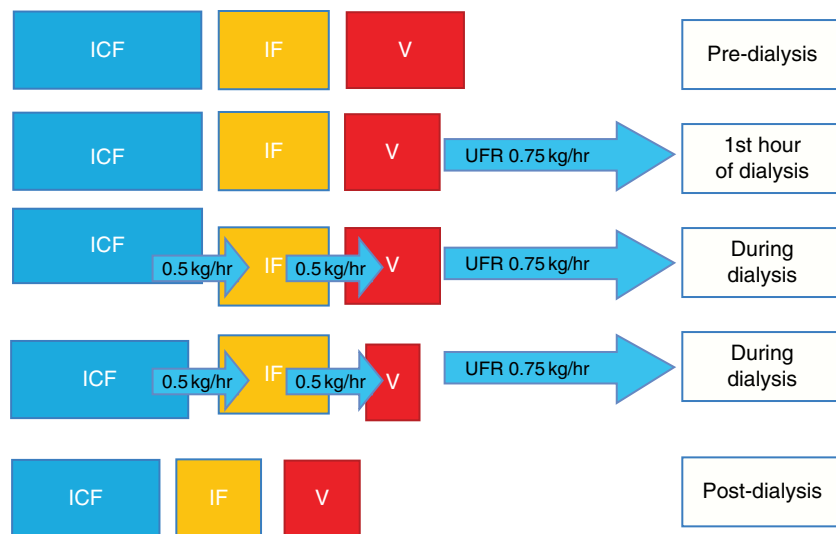


FIGURE 7.13 What happens when the refilling rate is lower than the ultrafiltration rate (UFR).

Manage thirst:

- Reduce the sodium in the dialysate.
- Reduce the sodium in the diet through reduction of salt (Davenport 2009a; Penne et al. 2010).
- Ensure good blood sugar control in patients with diabetes (Davenport 2009a; JBDS-IP 2016).
- Review diet for hidden fluid.
- Use ice cubes, smaller cups, etc. to assist patients in managing their fluid intake.
- Advise use of a jug to hold the total fluid allowance for that day, and then remove the equivalent amount of fluid as each drink is consumed.
- *Increase the treatment time.* The longer the treatment time, the lower the UFR required to remove the fluid.
- *Reduce the fluid removal gradually.* This means that patients complete haemodialysis with extra fluid still present. This approach can improve fluid removal over a longer period of time and reduce the risk of instability in the short term (which can necessitate a fluid bolus and minimal UFR). Also, IDH can trigger the thirst mechanism, leading to larger IDWGs. Maintaining stability not only improves clinical outcomes but also assists in managing IDWG and ensures the planned fluid removal happens accurately.

MANAGING REFILLING

As well as managing the UFR to minimise IDH, actions can be taken during haemodialysis to encourage refilling. These actions are:

- *Recline the patient and raise leg.* Also, reduce the effect of gravity on the blood supply to the head and central core, reclining the patient also promotes refilling.
- *Use isolated UF.* This also promotes refilling during isolated UF and the effect can prolong into haemodialysis. Isolated UF is the process of removing fluid in the dialyser. UF only occurs in the dialyser, so no dialysate or diffusion is utilised. Solutes are left behind in the blood and not removed. This leads to haemo-concentration within the blood which triggers the refilling process more rapidly. This allows greater volumes of fluid to be removed more rapidly and is better tolerated by patients. Often isolated UF is used at the start of haemodialysis treatments to remove fluid rapidly. The use of isolated UF should come with two cautionary notes:
 - No diffusion occurs during isolated UF, so this should not be included as part of the haemodialysis time and does not contribute to the Kt/V .
 - Solutes become more concentrated in the blood with isolated UF, so hyperkalaemia is a risk. Isolated UF should never be used initially with patients with high potassium. Haemodialysis, with diffusion, is the priority.

- *Maintain an adequate albumin and haemoglobin.* Albumin and haemoglobin help promote refilling. They create osmotic potential in the plasma to encourage refilling. Haemodialysis nurses should be aware that when these levels are low, patients are less likely to tolerate fluid removal.

DIALYSATE TEMPERATURE

The dialysate temperature can also be used to reduce IDH. This is the temperature that the dialysate is warmed to before it enters the dialyser. It fulfils the purpose of maintaining body temperature within the blood in the extracorporeal circuit, thus preventing hypothermia from cold blood re-entering the patient. Traditionally, the dialysate temperature has been set at 37 °C. However, recent studies have indicated this is not best option for the majority of patients (Roumelioti and Unruh 2015). Setting the standard dialysate temperature at 37 °C is above the majority of people's core temperature. This then means the patient is warmed, causing vasodilation and exacerbating IDH (Davenport 2009a). Studies have examined what is the best dialysate temperature to use. Van der Sande et al. (2009) found that cooling the dialysate temperature 0.5 °C below body temperature reduces IDH in patients with a history of hypotension. Selby et al. (2006a) found that using a dialysate temperature of 35 °C reduced hypotensive episodes, improved blood pressure, and reduced cardiac stunning during haemodialysis. A systematic review identified similar results (Selby and McIntyre 2006).

However, the case for cooling the dialysate or running it below 37 °C is not as clear-cut as this. There have been concerns that reducing the dialysate temperature will alter kinetics in the dialyser and reduce the movement and clearance of molecules. It has been identified that cooler dialysate does not affect the clearance of small molecules (Selby and McIntyre 2006b). However, the effect on middle molecule clearance is not known and under investigation by Maheshwari et al. (2015). Van der Sande et al. (2009) also found that cooling the dialysate could lead to shivering and cold symptoms during haemodialysis, making patients feel uncomfortable.

Current opinion suggests that cooling the dialysate is an intervention that can be used to manage frequent IDH events (Davenport 2006; Roumelioti and Unruh 2015). A Cochrane review found cooling the dialysate may reduce intra-dialytic hypotension, although this is uncertain and the long-term outcomes are currently unknown (Tsujimoto et al. 2019).

BLOOD-VOLUME MONITORING

Blood-volume monitoring has been promoted as a tool to predict IDH. It monitors the concentration of the blood, providing a blood volume reading which is tracked over the period of the haemodialysis treatment. It works under the assumption that if the blood is becoming more concentrated then there is less volume on the vascular compartment. It can be used to identify how well refilling keeps up with the UFR. If it becomes too negative, then this indicates the patient could drop their blood pressure. However, the value of blood volume readings is in question. Booth et al. (2011) identified little correlation between the blood volume reading and blood pressure. Often much emphasis is placed on the blood volume reading, when in reality, it is only one tool that adds to the nursing assessment of the patient.

SUMMARY OF MANAGING FLUID REMOVAL DURING HAEMODIALYSIS

Managing fluid loss in haemodialysis is more complex than calculating differences between dry and pre-dialysis weight. Haemodialysis nurses need to assess the correct amount and method of fluid removal for patients and ensure the target weight is accurate. Whilst changes in fluid status will occur slowly over time, haemodialysis nurses need to be vigilant to indications that the dry weight is changing. Poor management of fluid removal in haemodialysis can lead to rapid instability in haemodialysis, so it is critical that haemodialysis nurses manage this well.

ANTICOAGULATION

The final aspect of the haemodialysis prescription to be examined is anticoagulation. During haemodialysis a number of mechanisms trigger the clotting cascade and fibrin formation in the extracorporeal circuit. The mechanism for triggering the clotting cascade is complex, with causes including contact with foreign plastics in the circuit, sheer stress caused by vascular access use and the blood pump action (Davenport 2009b), cooling in the extracorporeal circuit, and stasis during blood pump stoppages and chambers. To counteract clotting within the circuit, heparin is normally administered into the arterial side of the circuit, either in the form of unfractionated heparin or low-molecular weight heparin (LMWH). Whilst both are valid ways of preventing clotting in the extracorporeal circuit, the latter has simplified this. However, the kidney nurse has an essential role to protect patients from the risks

associated with anticoagulation administration alongside balancing the prevention of clotting within the circuit.

Managing clotting within the circuit is a balancing process between minimising clotting in the circuit whilst not creating or exacerbating a bleeding risk in patients. Clotting can have many detrimental effects during a haemodialysis treatment, including:

- It blocks the circuit from clots, preventing flow through the circuit.
- Anaemia is exacerbated, caused by blood loss in the circuit either when:
 - The circuit becomes completely blocked preventing washback.
 - Clots left behind during washback which contain vital haemoglobin.
- Frequent alarms and blood pump stoppages due to pressure in the circuit. This will exacerbate clotting further and is also distressing for patients.
- Reduce clearance.
- Reduce vascular access function due to fibrin formation in vascular access. CVC are vulnerable to loss of function due to inadequate anticoagulation of the extracorporeal circuit.

As can be seen, clotting is more than just an inconvenience during haemodialysis treatments, but also affects the efficacy of the treatment, exacerbates anaemia and vascular access problems, and is distressing for the patient.

MANAGING CLOTTING WITHIN THE EXTRACORPOREAL CIRCUIT

Managing clotting can be through the administration of heparin, whether it be unfractionated heparin or LMWH. Heparin requirements can be assessed in a number of ways:

- Assessment of clotting directly in the circuit through:
 - Inspection following washback – ideally the circuit should be clear, with minimal clotting in chambers and minimal streaking in the dialyser;
 - Inspection during treatment for signs of clotting (Davenport 2009b).
- Pressure monitoring during treatment, as pressures will rise with increased clotting. This is often a late sign of clotting and difficult to rectify.

- Decline in online clearance readings during treatment – this is normally due to clotting.
- Excessive bleeding following needle removal, which indicates too much heparin was administered (Davenport 2009b).
- Use of clotting times through lab tests or bedside clotting block – these tests are only effective with unfractionated heparin but allow real-time adjustments through treatment (Mactier et al. 2011).
- Use the patient's weight in conjunction with assessment of the circuit, which can be used to dose LMWH (Davenport 2009b).
- Use a standard dose, as recommended with tinzaparin use (Davenport 2009b).

Prevention of clotting is essential to maintain the haemodialysis treatment, but using anticoagulation to do this needs to be balanced with the bleeding risk this introduces, as highlighted by Davenport (2006). In the majority of patients this requires the use of the minimum amount of heparin needed to prevent clotting.

Anticoagulation interrupts clot formation, which is used to prevent clot formation in the extracorporeal circuit. However, the anticoagulation will enter the patient's systemic circulation via the extracorporeal circuit, so will also anticoagulate the patient. The risk is minor, but whilst the patient is anticoagulated, bleeding will be harder to stop. UK Renal Association Guidelines recommend that unfractionated heparin or LMWH can be used for patients without increased bleeding risk, but these should be avoided in patients with a high risk of bleeding or heparin-induced thrombocytopenia (HIT) (Ashby et al. 2019). Therefore, haemodialysis nurses need to ensure that anticoagulation is only administered to patients with no known bleeding risk.

Sometimes bleeding is not evident, so haemodialysis nurses need to be aware of the situations where patient may be deemed to have a high bleeding risk, so heparin can be avoided. Signs of a high bleeding risk without observed bleeding can include:

- head injury or altered mental neurological status;
- coffee ground vomit;
- melaena or black faeces;
- liver failure;
- raised INR or low platelet level;
- unexplained bruising;

- fractures or after falls;
- post-surgery or post-procedure

If heparin cannot be administered, then high BFR and boluses of saline directly into the arterial side of the extracorporeal circuit can be used to minimise clotting in the circuit. The volume of saline administered can be added to the fluid removal during haemodialysis. However, high BFRs are not always possible, especially if the vascular access will not allow this or the patient has a risk of disequilibrium syndrome. Sometimes these actions will not prevent clotting of the circuit and the circuit needs to be changed mid-treatment. Ideally the circuit should be changed before the washback is lost, to prevent blood loss from the haemodialysis patient.

Citrate anticoagulation has been suggested as an alternative to heparin use in the patient with a high bleeding risk (Ashby et al. 2019), especially as it is easy to reverse the effects through a calcium infusion (Davenport 2006). Citrate anticoagulation reduces calcium levels and creates a risk of cardiac arrhythmias due to hypocalcaemia. Whilst this can be managed with calcium infusions, this is difficult to do well in a non-critical care environment (Clark et al. 2008).

HEPARIN-INDUCED THROMBOCYTOPENIA (HIT)

Occasionally, haemodialysis patients can develop HIT from heparin use (Davenport 2009b). Although rare, nurses need to be aware how to manage these patients. HIT is normally an immunological condition where the body has created antibodies against heparin (Chong 2003). Whilst thrombosis and acute systemic sensitivity reactions are often mentioned as signs of HIT, patients often present with a low platelet count or a purpuric (non-blanching) rash.

Heparin administration should stop immediately as this can escalate to anaphylactic-type reactions to the heparin (Chong 2003). HIT is a reaction to all heparin, so HIT developed from unfractionated heparin is also likely to escalate if the patient is then transferred onto LMWH (see Figure 7.14). Alternative anticoagulants that can be used in the presence of HIT include argatroban, fondaparinux, or danaparoid (Chong 2003; Ashby et al. 2019).

Whilst anticoagulation management is often seen as the remit of medical staff, as it is a prescribed drug, haemodialysis nurses are often the personnel that monitor the effect of anticoagulation on haemodialysis. Nurses have a responsibility to dispense medications in the context of treatments and other healthcare needs (Nursing and

Unfractionated Heparin	Low-Molecular Weight Heparin
Short half-life, so removed systematically promptly (Davenport, 2009b)	Longer half-life, so stay active systematically for longer (Davenport, 2009b)
Require continuous infusion throughout treatment	One-off bolus at start of treatment
Dosing can be changed through treatment in response to clotting	Dosing can only be changed in between treatment in response to clotting
Protamine is more effective as an antidote, to reverse the effects of anticoagulation (Davenport, 2009b)	Protamine is less effective with LMWH (Davenport, 2009b)
Higher interference with lipid metabolism, worsening lipid profiles (Davenport, 2009b)	Less interference with lipid metabolism, leading to improved lipid profiles (Davenport, 2009b)
Increase in osteoporosis (Davenport, 2009b) NB. Only proven in pregnant women	Less incidence of osteoporosis (Davenport, 2009b)
Slightly higher frequency of HIT (Davenport, 2009b)	HIT is less frequent (Davenport, 2009b)
Lower cost (Davenport, 2009b)	Higher cost (Davenport, 2009b)
Less convenient to dose and administer (Mactier et al, 2009)	More convenient to dose and administer (Mactier et al, 2009)

FIGURE 7.14 Unfractionated heparin v. LMWH.

Midwifery Council 2015). For haemodialysis nurses this means managing anticoagulation to minimise clotting in the circuit, avoiding heparin use due to an identified, often transient, bleeding risk, and managing clotting with alternatives to heparin. Haemodialysis nurses need to be aware of all these factors to ensure patients receive haemodialysis where the actions to minimise clotting are considered against the bleeding risk introduced to patients.

VASCULAR ACCESS FOR HAEMODIALYSIS

Vascular access is a large and important aspect of haemodialysis. Vascular access provides the means

to remove and return the blood in and out of the circulation. Vascular access is often referred to as the cornerstone of haemodialysis, as without it haemodialysis cannot be performed. However, vascular access continues to be a point of vulnerability in haemodialysis care.

There are three types of vascular access used for haemodialysis: AVF, AVG, and tunnelled CVCs. The types of vascular access are summarised in Box 7.3. However, no type of vascular access is perfect with different complications associated with each type of vascular access. Figure 7.17 summarises the complications associated with each type of vascular access.

BOX 7.3

TYPES OF VASCULAR ACCESS USED FOR HAEMODIALYSIS

Arteriovenous fistula

This is a surgical joining of an artery to a vein. This allows diversion of the blood supply from the artery to the vein, with strong high flow arterial blood supply in the vein. The vein becomes arterialisised with a higher flow and pressure than is normal for a vein, a larger vein diameter, and thickening of the vein wall. This creates a vessel that provides the high flows required for haemodialysis as well as robust enough to cope with repetitive cannulation for each haemodialysis session over periods of years.

Figure 7.15 demonstrates the anatomy of a radiocephalic AVF, attaching the radial artery to the cephalic vein to use the

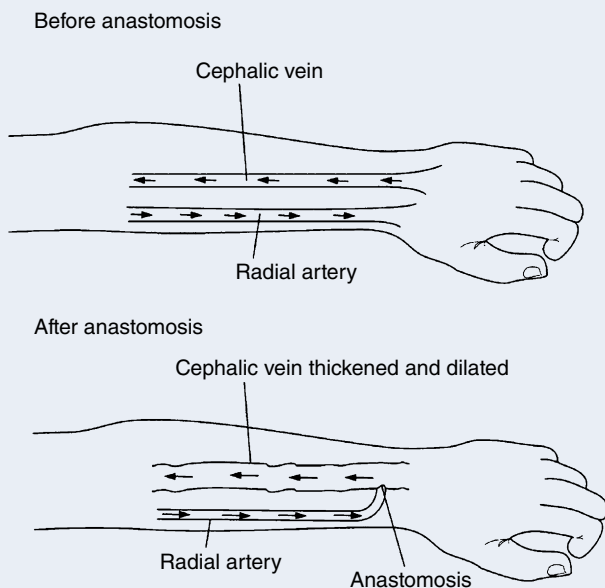


FIGURE 7.15 Arteriovenous fistula.

cephalic vein for cannulation. The joining of the artery and the vein is known as the anastomosis. Other common AVFs are brachiocephalic (using the brachial artery connected to the cephalic vein at the elbow) and brachio basilic (using the brachial artery connected to the basilic vein). The latter often requires superficialisation to raise the basilic vein closer to the skin surface for cannulation.

Arteriovenous graft

This is insertion of a plastic tube between the artery and the vein. PTFE is the common material used, although new plastics are regularly being tested and launched to reduce complications related to AVG use. The latest developments include biosynthetic grafts that use ovine (sheep) collagen (Koens et al. 2015) and early cannulation grafts (Al Shakarchi et al. 2015). Figure 7.16

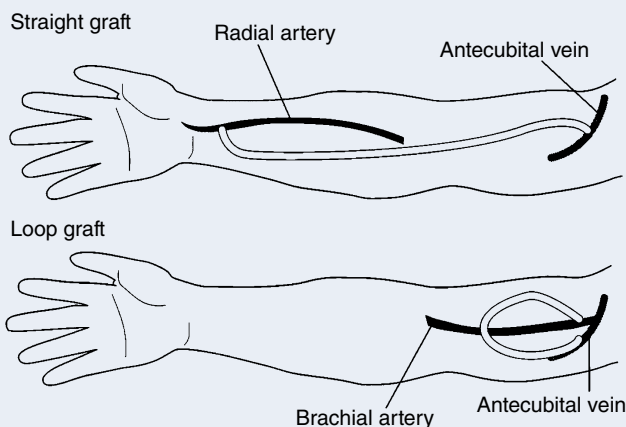


FIGURE 7.16 Arteriovenous graft.

provides an example of a forearm AVG. AVGs in the leg are common practice, and necklace AVGs can be used where vascular access options are limited. Once inserted AVG care is similar to care of AVFs, with cannulation into the plastic tubing for each haemodialysis session.

Central venous catheter

CVCs are wide-bore catheters that sit in a central vein. Common veins used are internal jugular vein and femoral

vein. The subclavian vein is normally avoided due to the high risk of developing central venous stenosis (Kumwenda et al. 2015). CVCs can be tunnelled central venous catheters (TCVC) or non-tunnelled central venous catheters (NTCVC). NTCVC are not recommended for long-term use due to the high infection risk (Kumwenda et al. 2015). TCVCs sit in a subcutaneous tunnel underneath the skin before entering the circulation and include a cuff within the tunnel to maintain the position of the TCVC.

AVF	AVG	TCVC
Infection – lowest rate (Almasri et al. 2016)	Infection (Almasri et al. 2016)	Infection – highest rate (Almasri et al. 2016)
Failure to mature, leading to a high primary failure rate before AVF is cannulated (Al-Jaishi et al. 2016)	Bleeding from degradation of AVG material	Poor flow rate/catheter dysfunction (Kumwenda et al. 2015)
Cannulation complications • Inability to cannulate (van Loon et al. 2009) • Missed cannulation (van Loon et al. 2009) • Pain and associated cannulation anxiety (Figueiredo et al. 2008) • Infiltration and associated bruising / haematoma (van Loon et al. 2009) • Damage to surrounding structures including nerves and arteries		Insertion complications • Damage to surrounding arteries • Air embolism • Cardiac arrhythmias • Pneumothorax • Bleeding and bruising
Aneurysm and stenosis formation from repetitive cannulation (Al-Jaishi et al. 2016)	Aneurysm and stenosis formation from repetitive cannulation (Kumwenda et al. 2015)	Central venous stenosis (Nicholas et al. 2017)
Thrombosis leading to failure – lowest rate (Al-Jaishi et al. 2016)	Thrombosis leading to failure – highest rate (Kumwenda et al. 2015)	Fibrin build-up in lumens and fibrin sheath
Steal syndrome causing peripheral limb ischaemia (Al-Jaishi et al. 2016)	Steal syndrome causing peripheral limb ischaemia (Kumwenda et al. 2015)	

FIGURE 7.17 Complications of the three vascular access types.

AVF is considered the best option for haemodialysis, as it is associated with the lowest mortality rate, the least complications, and has the best longevity (Almasri et al. 2016; Ng et al. 2011). AVG is the second-best option, as mortality, complications, and longevity are worse than AVF but better than a tunnelled CVC (Almasri et al. 2016; Ng et al. 2011). However, whilst AVG may be associated with slightly worse outcomes than AVF, AVGs are used when an AVF is not feasible, so selection bias tends to confound studies comparing outcomes from AVF and AVG (Almasri et al. 2016). A tunnelled CVC is the third-best

option but is associated with highest rate of mortality, complications, and the worst longevity (Almasri et al. 2016; Ng et al. 2011). In particular, the use of tunnelled CVCs for haemodialysis is associated with much higher risk of infection and higher hospitalisation rate (Ng et al. 2011).

There is large variation in vascular access provision, both internationally and across the UK (UK Renal Registry, 2023; Port et al. 2017). Japan and Russia maintain a high rate of AVF use of over 90%, whilst countries like Canada struggle to maintain AVF use above 50% (Port et al. 2017). Interestingly the DOPPS data provide an AVF and AVG rate

in the UK of 84%, whereas estimations from the UK Renal Registry data (2023) set this at approximately 70%. The DOPPS only used a selection of UK units to collect data. As there is significant variation across the UK in AVF rates, the difference could be accounted for through the selection of units for the DOPPS data collection. Due to likely better outcomes for patients who use an AVF for haemodialysis, there is much focus on improving AVF rates within the haemodialysis population, although current guidelines encourage considerations of individual patient preference too (Aitken et al. 2023).

ACHIEVING DEFINITIVE ACCESS PROVISION

As the figures tend to indicate, achieving definitive access provision is challenging. The many factors that impact this include:

- *Patient choice.* Patients often make decisions based on the experience of others. McCarthy et al. (2015) identified that vicarious learning from other patient experiences often affects modality choice, and the same could be extrapolated for vascular access choice. Similarly, concern then develops that poor experience of cannulation and AVF/AVG use will dissuade patients from having an AVF/AVG. Cavanaugh et al. (2009) identified that patients with more knowledge about dialysis were more likely to choose an AVF for haemodialysis use. Attention needs to be given as to how patients are prepared to make choices about their vascular access.
 - *Preparation for haemodialysis.* As AVF and AVG use requires prior planning, which can be difficult to predict and ensure functioning access is in place once patient start haemodialysis. However, once on haemodialysis, patients often like to maintain the status quo, and are more reticent to change the type of vascular access (Xi et al. 2011).
 - *Service structure to ensure timely vascular access provision.* Much work has been done to improve timely access provision. Oliver et al. (2015) performed an appraisal of vascular access in Scotland, particularly focussing on what led to success. Keys to success include having:
 - proper patient support and education about vascular access;
 - clear pathways for access formation in a timely manner with allocated surgical and radiological time;
 - a co-ordinator to prioritise the correct patients for vascular access surgery;
 - regular vascular access MDT meetings;
 - adequate assessment and surveillance of AVF/AVG;
 - access to radiological support to salvage of failing vascular access.
- The British Renal Society's (now UK Kidney Association) Vascular Access Special Interest Group (BRS VA) performed a survey into vascular access services within the UK (Kumwenda et al. 2017). They identified that much of the required structure is present in kidney units across the UK, despite the variation in vascular access provision. This may mean we haven't yet identified what leads to success or that this structure takes time to have an effect on vascular access provision rates.
- *Well-trained staff to form and care for vascular access.* The DOPPS identified that surgical training that included AVF formation led to surgeons who had more successful AVF formation procedures (Goodkin et al. 2010). The DOPPS also identified that vascular access type was associated with centre preference rather than any other factors (Port et al. 2017), indicating staff preference highly dictates vascular access provision. However, vascular access provision is not just about formation but also how you care for the vascular access once in place. In particular, optimum cannulation of an AVF and AVG is widely accepted to affect survival of the AVF/AVG, but cannulation practice continues to vary across the UK (Fielding et al. 2016b). Knowledgeable haemodialysis nurses in the assessment and care of vascular access is essential to maintain good outcomes and longevity of AVF/AVG (Fielding et al. 2016b; Oliver et al. 2015).
 - *Surveillance programmes to detect failing vascular access.* The repetitive use of AVF/AVG affects the function of the AVF/AVG, ultimately leading to failure. Surveillance of AVF/AVG is essential to ensure failing access is detected and corrected, before AVF/AVG function is lost completely (Kumwenda et al. 2015; Oliver et al. 2015). An ACCESS algorithm to assist with assessment and surveillance of AVF/AVG has been created (Figure 7.18). This includes basic nursing assessment pre-cannulation through to more complex surveillance measurements that assesses flows through the AVF/AVG and detects stenosis development, allowing pre-emptive correction.
- Many factors affect the prevalence of AVF and AVG use. These include having adequate formation of AVF/AVG in a timely way in preparation for haemodialysis use, but also preserving the function of the AVF/AVG once in use. Regardless of vascular type used, the complications associated with all vascular access needs to be minimised. Figure 7.19 summarises the many facets associated with promoting AVF/AVG use.

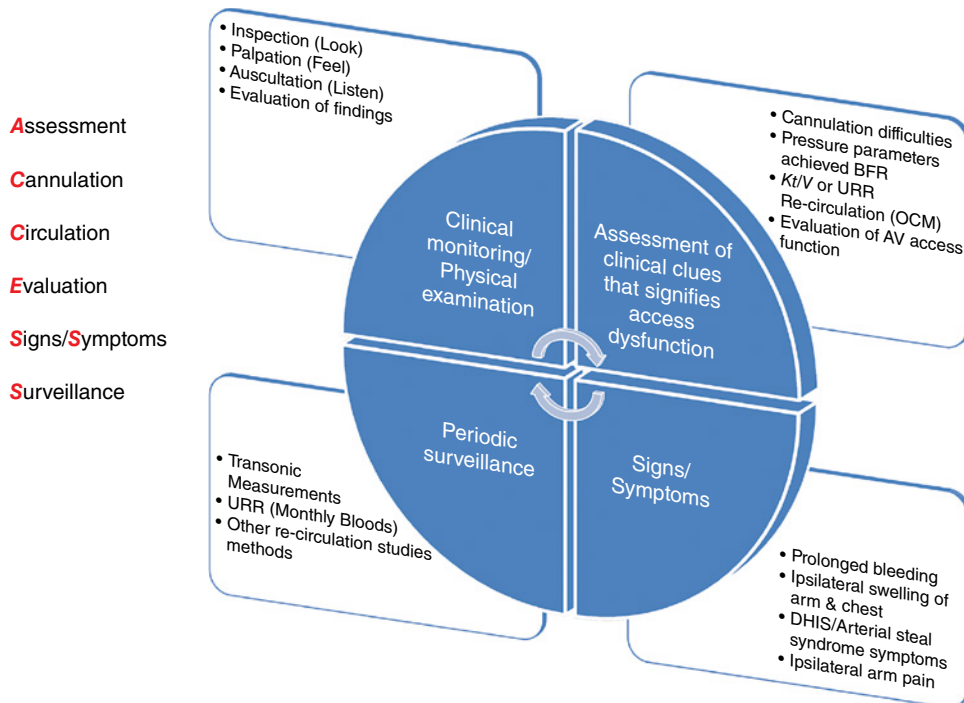


FIGURE 7.18 ACCESS for assessment and surveillance of AVF/AVG. *Source:* Reproduced with kind permission from Kristine Paule.

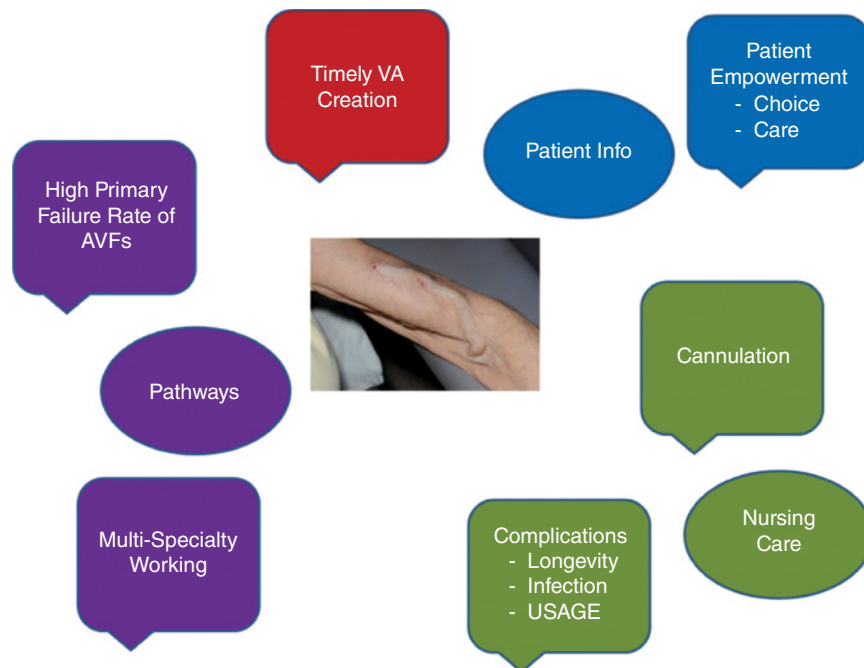


FIGURE 7.19 Multi-faceted approach to promote AVF/AVG use.

CARE OF AVF AND AVG

POST-OPERATIVE CARE

The post-operative care of an AVF/AVG is similar to most post-operative care. The wound from the anastomosis formation needs to remain clean and dry, with a dressing intact until it has healed. This prevents infection at the wound and promotes healing. Often the wound will be stitched either with soluble stitches or non-soluble stitches that need to be removed once the wound has healed. A brachio basilic (upper arm) AVF and AVG may involve more complex wounds, but the principles remain the same. As with any operation, whilst a wound is present there is a bleeding risk from the wound. Consideration needs to be given to management of anticoagulation and clotting of the circuit, and anti-thrombolytic use to treat TCVC dysfunction needs to be avoided at all costs.

There are also more specific considerations when caring for an AVF/AVG post-formation. Firstly, a good blood supply to a newly formed AVF/AVG will help prevent failure from thrombosis and promote maturation of the AVF. Hypotension during or post-haemodialysis can bring about thrombosis of the new and vulnerable AVF/AVG. The dry weight can be increased by 0.5–1 kg for 2–4 weeks post-AVF/AVG formation to prevent thrombosis of the newly formed access. Also, increased anticoagulation of the haemodialysis circuit may prevent thrombosis of the new AVF/AVG. The haemodialysis nurse needs to use clinical judgement as to which is a priority, preventing bleeding from the wound or minimising clotting in the haemodialysis circuit, which may promote thrombosis of the new AVF/AVG.

Secondly, if the patient has not had an AVF/AVG before, they need to be taught how to care for the AVF/AVG. They need to be shown how to check it is working, by checking the thrill, plus the importance of keeping the wound dry and how to care for their AVF/AVG to avoid failure. Patients should be advised to avoid tight clothing, heavy lifting, BP measurements, and non-haemodialysis related venepuncture or cannulation on their AVF/AVG limb. Once the wounds have healed, the patient can also exercise the AVF to promote maturation of the vein. This involves engorging the AVF vein three to four times a day, using a tourniquet applied lightly, and squeezing their hand for two to three minutes. Often squeeze balls are provided for the patient to do these exercises. This exercise should continue until the AVF is fully mature. AVGs do not need to mature in the same way as AVFs so this exercise is not required.

CANNULATION OF THE AVF/AVG

Once mature, the AVF/AVG will be ready to cannulate for use. Cannulation is critical to the success of AVF and AVG use:

- Cannulation needs to be successful to allow use for haemodialysis and obtain optimal flows.
- Cannulation damages the AVF/AVG vessel, ultimately leading to failure of the AVF/AVG.
- Cannulation affects the patient's experience of haemodialysis.

CANNULATION TECHNIQUES TO PRESERVE AVF/AVG FUNCTION

It is well known that the repetitive nature of cannulation for haemodialysis leads to stenosis and aneurysm formation in the AVF and AVG. Stenosis formation is the main cause of AVF thrombosis as it slows blood flow through the vessel (Fulker et al. 2017). In particular, mechanisms for stenosis development include development of intimal hyperplasia from scarring, inflammation, and turbulent flow in the vessel (Fulker et al. 2017). Aneurysms develop from weakening of the vessel wall from repetitive cannulation and can exacerbate in the presence of an outflow stenosis (Kronung 1984).

Kronung first described three cannulation techniques that either promote or minimise stenosis and aneurysm development (Figure 7.20). These are rope ladder, buttonhole, and area puncture. Kronung's (1984) work was based on the presumption that aneurysms and stenoses can be minimised by either maximising the length of the fistula or graft used for cannulation, which he describes as minimising 'punctures per unit area', or by using the same cannulation site each time. This minimises aneurysm and stenosis development. Therefore, Kronung (1984) recommended rope ladder or buttonhole cannulation and avoidance of area puncture. The three techniques are described in the next sections.

Buttonhole technique

The buttonhole technique was first introduced by Twardowski and Kubara (1979). It involves needling each cannulation site in the same manner each time. The needle enters the same hole in the skin, travels the same route to the vein both in depth and direction and then enters the vein at the same point (Fielding et al. 2016b; Pergolotti et al. 2011). This insertion of the needle into the same point develops a track of scar tissue and weak point on the vein

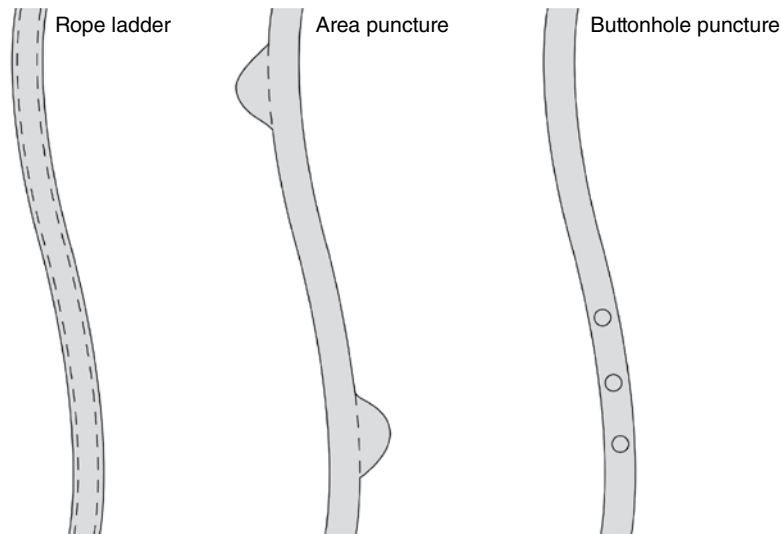


FIGURE 7.20 Cannulation techniques, as described by Kronung (1984).

wall (Fielding et al. 2016b) (Figure 7.21). The technique has three steps:

1. Remove the scab from the previous needle insertion.
2. Follow a track development phase where 1–3 of the same nurses cannulate the AVF in the same manner each time.
3. After 6–12 cannulations, convert to blunt / dull needles, allowing multiple cannulators (British Renal Society Vascular Access Special Interest Group 2016a; Fielding et al. 2016b).

Whilst each site is cannulated in the same manner each time, the buttonhole technique can involve two to four different sites (BRS VASIG 2016b; Twardowski and Kunara 1979). This allows resting of sites for some haemodialysis sessions, which is particularly necessary when patients have haemodialysis more frequently than thrice weekly.

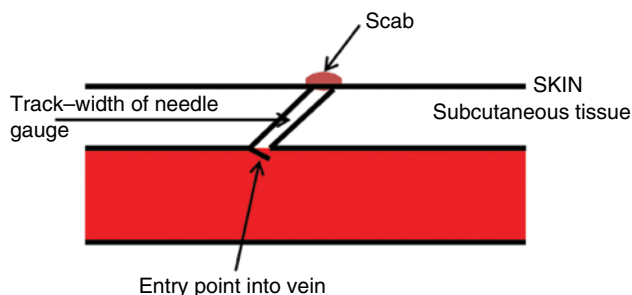


FIGURE 7.21 Buttonhole site.

The buttonhole technique has been associated with a higher infection risk leading to some units avoiding this technique (Grudzinski et al. 2013; MacRae et al. 2012; O'Brien et al. 2012). However, some units have been able to use this technique without problems with infection (Vaux et al. 2013) or have overcome infections to identify better practice (Ball 2010; Labriola et al. 2011; Nesrallah et al. 2010; van Loon et al. 2010). The BRS VA and Vascular Access Society of Britain and Ireland (BRS VA and VASBI) (2018a) (Fielding et al. 2016b) have produced clinical practice recommendations on how to perform buttonhole and minimise infections. This technique is currently recommended for AVF only (BRS VA and VASBI 2018a).

Rope ladder technique

The rope ladder technique was originally described as 'equal distribution of punctures along the whole length of the fistula vein'. This has led to rope ladder being described as cannulation that moves up the vein and then down again. However, this definition has often led to claims that rope ladder is being performed, when really this is area puncture with associated aneurysm and stenosis development (Fielding et al. 2016b; Vaux et al. 2013). BRS VA and VASBI (2018a) have further defined rope ladder to delineate it from area puncture:

- Each cannulation occurs 0.5–1 cm above the previous site.
- Each cannulation moves up the vein in systematic manner and once the top of the vein is reached, cannulation starts at the bottom again.

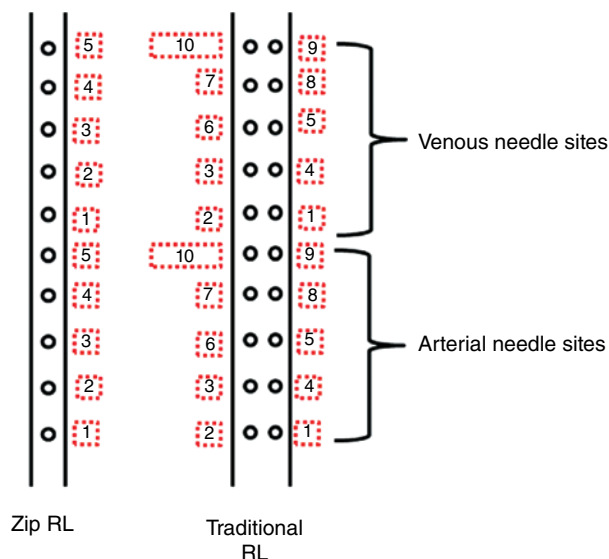


FIGURE 7.22 Site rotation in rope ladder.

- Cannulation can move side to side in veins wider than 9 mm diameter, but this needs to still be done in a systematic manner (Figure 7.22).
- Cannulation sites should cover a minimum distance of:
 - 8 cm when both arterial and venous needle sites are on the same segment of vein.
 - 5 cm for each site, when cannulation sites are on different segments of vein (BRS VA and VASBI 2017a).

The rope ladder technique has been considered the default technique within the UK. However, the rope ladder technique has been poorly investigated, with a majority of research studies based on various definitions of rope ladder and study methods only comparing rope ladder with buttonhole technique. Rope ladder technique can lead to a harder needle insertion than buttonhole, with higher frequency of haematoma and cannulation problems (Twardowski and Kunara 1979; van Loon et al. 2010; Vaux et al. 2013). Whilst some studies have proven the opposite (Chow et al. 2011; Smyth et al. 2013), the reality is that studies are often poorly designed to draw accurate conclusions (Grudzinski et al. 2013). Rope ladder can be used on both AVF and AVG and is the recommended technique for AVG (BRS VA and VASBI 2018a).

Area puncture

Area puncture is cannulating in the same area each time, but not in a planned or systematic manner. The description

of area puncture is also vague. BRS VA and VASBI (2018a) have defined area puncture as cannulation that covers smaller areas than those defined by the rope ladder definition. Area puncture is not recommended for use, as it leads to aneurysm development and earlier AVF/AVG failure. Despite this, area puncture is prevalent, with an estimation of area puncture use at 65.8% in an international study that included the UK (Parissotto et al. 2014).

The debate as to whether rope ladder or buttonhole is better continues, with variation in practice across the UK. Regardless of the outcome of this debate, haemodialysis nurses need to strive to not use area puncture.

GOOD CANNULATION TECHNIQUE

Needle insertion can be a painful and anxiety-provoking procedure for patients (Casey et al. 2014; Taylor et al. 2016). There is a strong need for haemodialysis nurses to perform needle insertion well. Techniques that may promote good needle insertion are not well evidenced, with some research evidence from Canada (Harwood et al. 2016).

Good assessment of the vessel prior to cannulation leads to more successful cannulation (Harwood et al. 2016). The look, listen, feel assessment is used pre-cannulation to identify complications and determine where and how to insert the needle. The look part involves visual assessment of the vessel and limb; the feel part involves palpation of both the vessel and thrill; the listen part involves auscultation of the bruit (Fielding et al. 2018; BRS VA and VASBI, 2018a). This can also involve gathering a history about previous cannulations (Harwood et al. 2016). This prepares the cannulator (the person inserting the needle) in determining where to insert the needle and performing the cannulation in a considered and accurate manner. Needles should never be inserted 'blind' without an idea of where the vessel is.

PLANNING CANNULATION

Much has been discussed in the literature about the need to plan buttonhole track development, using only one to three nurses to cannulate the sites. However, in reality all cannulation needs planning and communication (BRS VA and VASBI, 2018a). Rope ladder technique also needs to be planned to be able to undertake this in a systematic manner. Planning not only allows communication of how to cannulate the vessel, but also dissemination of experience. It is recognised that cannulation skill develops with experience and that individual cannulators sometimes develop better skills than others. Good cannulation practice within a unit requires experienced cannulators to support less

experienced cannulators, especially when cannulating difficult AVF/AVGs (Harwood et al. 2016). This can be completed through physical presence and support during individual cannulations (Harwood et al. 2016). Nursing teams need to consider how they can communicate the plan of cannulation, to allow knowledge of individual cannulations to be transferred between staff. This may involve facilitating patient involvement in the cannulation, so the patient can provide guidance (Harwood et al. 2016), but also requires support through documentation.

SELF-AWARENESS OF THE CANNULATOR

Cannulation is an emotive subject that is stressful for both the patient, but also the cannulators, especially if the cannulation is difficult. Cannulators need to be aware that there may be times when they are unsuccessful with cannulation and need to ask for help from others, even if they have been successful with that AVF/AVG previously (Harwood et al. 2016). It is recommended that nurses only attempt cannulation twice before getting assistance from others (BRS VA and VASBI, 2018a).

GENTLENESS AND SENSITIVITY THROUGHOUT THE CANNULATION

If it is recognised that cannulation can be difficult for both patients and cannulators, then cannulators need to approach this in a sensitive manner. They need to recognise patients' anxiety and give this time (which is often in short supply), respect, and consideration (Harwood et al. 2016). Harwood et al. (2016) identify that cannulators need good communication skills to deal with this element of cannulation. The cannulation procedure also requires an element of pragmatism, as regardless of anxiety, haemodialysis and the related cannulation is a life-sustaining procedure that is necessary. Cannulators need skill to balance empathy with an anxious patient and pragmatism to perform the needling procedure (BRS VA and VASBI, 2018a). This should be reflected in the actual needle insertion procedure, with the insertion performed with a gentle and consistent movement that occurs in a timely manner.

CORRECT PLACEMENT OF THE NEEDLES

The aim of cannulation is get the needle into the centre of the vessel. Assessment of the vessel should allow cannulators to determine what angle and direction of needle insertion is required to achieve this. The technique (buttonhole or rope ladder) will help determine where to place the

needle on the vessel length. However, there are certain areas that should always be avoided:

- Needles should never be inserted at the anastomosis and ideally placed at least 2 in. away from this.
- Needles should not be placed too far away from the anastomosis. Ideally there should be an audible bruit at both needling sites.
- Sites with an indication of complications should be avoided. This may be bruising, redness, inflammation, or signs of poor skin integrity.
- Divisions on the veins should be avoided, as cannulation at this site often leads to infiltration and bruising/haematomas.

TOURNIQUET USE

Tourniquet use with an AVF during needle insertion makes the vein firmer and plumper to needle, making the centre of the vein easier to determine. BRS VA and VASBI (2018a) and Ball (2010) recommends a tourniquet should always be used with AVF cannulation. A tourniquet is not necessary with an AVG, as it will not alter the firmness or diameter of the vessel.

EXPERIENCED AND WELL-TRAINED NURSES

Harwood et al. (2016) identified that training and experience of staff when learning how to cannulate is critical. Cannulation skills develop over time and with experience, but new cannulators also need good training and mentorship to develop their cannulation skills. Fielding et al. (2016b) has identified that cannulation requires well-trained staff to be successful, but also requires monitoring of cannulation practice to ensure procedures are adhered to.

These points provide some guidance on the skills needed to insert a needle well into AVF/AVG. It should be noted that AVG cannulation often feels different as the vessel wall is tougher to insert a needle through. Cannulators often describe a double 'pop' sensation when inserting a needle into the AVG, where it feels as if you passed through the wall twice as you pass through the multiple layers of the AVG wall. This leads to inexperienced cannulators inserting needles into the AVG that are too shallow, especially as a flashback of blood may be seen before the needle passes completely into the vessel lumen.

Despite the importance of good cannulation technique, there is very little exploration of this area of practice. Further research is required to identify what is good cannulation practice and reduce variation in cannulation practices.

TUNNELLED CENTRAL VENOUS CATHETER CARE

As TCVCs should ideally be avoided, there has been less attention paid to TCVC care. Much current practice development focusses on how to improve AVF and AVG rates. However, the care of TCVC is essential to minimise the complications associated with their use. There are two main complications that need to be prevented and managed on a day-to-day basis – infection and flow problems.

PREVENTION OF INFECTION IN TCVC

The biggest concern with TCVCs is the risk of infection. Ravani et al. (2013) identified that TCVCs have a much higher risk of mortality and infection than AVFs and AVGs. There are a number of strategies that can be used to prevent infections when using a TCVC, including:

- Screening of patients for MSSA and MRSA with appropriate decolonisation (Nicholas et al. 2017).
- Use of sterile gloves and sterile equipment to access a TCVC.
- Use of a two-person procedure to connect patients to haemodialysis, allowing one person with sterile gloves to access and handle the TCVC and a second person to operate the non-sterile haemodialysis machine.
- Use of a non-touch technique to handle TCVC connections and disconnections (Nicholas et al. 2017).
- Use of antibiotic or antimicrobial locks (Jaffer et al. 2008; Yon and Low 2013).
- Use of chlorhexidine (or povidone iodine if allergic to chlorhexidine) to clean the exit site (Loveday et al. 2014).
- Use of a sterile, transparent, semi-permeable dressing on the exit site (Loveday et al. 2014). Recently, chlorhexidine dressings have been adopted for use in haemodialysis catheters (Nicholas et al. 2017) after successes in critical care settings (Timsit et al. 2012). NICE (2015) now recommends that the Tegaderm CHG (2% chlorhexidine gluconate) dressing, which includes a chlorhexidine patch, should be used on all CVCs (NICE 2015).
- The exit site should be examined at each dialysis session for signs of infection (Aitken et al. 2023; Loveday et al. 2014; Nicholas et al. 2017).
- Prompt treatment of identified infections with intravenous antibiotics to minimise serious infectious complications associated with TCVC infection (Aitken

et al. 2023) Prevention of infection is not just important to prevent morbidity and mortality, but also appears to be associated with central venous stenosis development (Nicholas et al. 2017). Central venous stenosis can affect the existing and future success of vascular access (Nicholas et al. 2017), causing flows problems in TCVCs and future upper-body AVFs and AVGs.

PREVENTION OF FLOW PROBLEMS

TCVCs can regularly experience reduced flow rates during haemodialysis, leading to frequent pressure alarms throughout haemodialysis and an inability to dialyse effectively. Causes of flow problems can include thrombosis or fibrin in the lumen or at the catheter tip, build-up of a fibrin sheath, catheter malposition, pinch-off syndrome (kinked or twisted catheter), the catheter sitting close to the wall of the vein (Godelieve 2015), or migration of the catheter out of the vessel. The latter four complications are mechanical and often require manipulation of the catheter position by the medical team. However, thrombi and fibrin build-up are regular problems with TCVCs often because of long-term use.

Flushing and locking of the TCVC can affect fibrin and thrombi build-up (Godelieve 2015). Pulsatile flushing, where insertion of the flush stops and starts, builds turbulence in the lumen, clearing it more effectively (Ferroni et al. 2014). Insertion of the lock using positive pressure locking, where the catheter lumen is clamped before releasing pressure on the end of the syringe, is thought to create a positive pressure on the end of lumen preventing the back flow of blood into the lumen (Godelieve 2015). Both these techniques can be used with a TCVC to prevent flow problems, through prevention of thrombi and fibrin in the lumen. If flow problems do develop, anti-thrombolytic agents like urokinase (Godelieve 2015) and alteplase (Zacharias et al. 2003) can be used to dissolve fibrin build-up (Aitken et al. 2023).

Again, these strategies are not just important to prevent TCVC dysfunction, but also help minimise infection through prevention of biofilm buildup (Godelieve 2015; Ferroni et al. 2014). It is also important that training and education of staff is undertaken to ensure they are aware of good TCVC care.

SUMMARY OF VASCULAR ACCESS

Vascular access care is critical for the success of haemodialysis and minimising morbidity and mortality for haemodialysis patients. Whilst AVF and AVG provision is an essential part of good vascular access care, the way

haemodialysis nurses care and cannulate AVFs and AVGs is critical for the longevity of the vessel, and good TCVC care can minimise complications and associated morbidity and mortality. Haemodialysis nurses have an essential role in provision of care for vascular access and promoting good outcomes for patients.

A repetitive theme throughout this chapter is the good training of haemodialysis nurses to be able to provide haemodialysis well, which includes good vascular access care. Potentially this is an area to highlight due to poor provision and lack of respect for the necessity of good education of haemodialysis nurses. The evidence base for much vascular access care is poor or medicalised through interest from the medical profession. Whilst the latter should not be criticised, haemodialysis nurses are the true experts of vascular care and need to fill the void of research evidence in this area.

ASSESSMENT AND MONITORING DURING HAEMODIALYSIS

Monitoring the patient through the haemodialysis treatment is a significant part of the haemodialysis nurses' role. Whilst haemodialysis machines provide a monitoring function, the monitoring on the haemodialysis machine needs interpretation and application to the individual situation.

COMMON COMPLICATIONS DURING HAEMODIALYSIS

Monitoring of the patient requires knowledge of potential complications that can occur in haemodialysis. If haemodialysis nurses are aware of potential complications and how to prevent these, then adverse events can either be avoided or at least minimised. There have been a number of recent studies that have examined adverse incidents in haemodialysis.

Fielding et al. (2016a) used a trigger tool approach to monitor adverse incidents during haemodialysis. This identified frequent adverse events during 566 haemodialysis treatments. These included:

- symptomatic hypotension;
- high UFR;
- more than one attempt to insert a needle into an AVF/AVG (multiple cannulation attempts);
- prolonged bleeding post-haemodialysis;

- other vascular access problems including problematic flows and haematoma;
- hypoglycaemia;
- delayed start to treatment (i.e. late on treatment);
- machine failure during treatment;
- error programming the dialysis prescription.

Many of these frequent complications have already been discussed through the chapter – patients should always be monitored for development of these complications.

Haemodialysis nurses also need to be aware and have vigilance that haemodialysis machines can have faults and humans can make errors when preparing the machine. This requires adequate training of haemodialysis staff to minimise error and an awareness of what can go wrong in haemodialysis treatments (Rylance and Fielding 2014). Rylance and Fielding's (2014) work also highlighted that whilst rare, critical incidents are of concern, common adverse incidents are also of concern, as well as more generic adverse incidents that patients are vulnerable to, such as falls or pressure ulcers. Rylance and Fielding (2014) highlight the following concerns:

- bleeding and haemorrhage from vascular access
- venous needle dislodgement (VND)
- infection
- failure of equipment and disposables for haemodialysis
- error in use of haemodialysis equipment
- medication errors

Bleeding from vascular access requires a proper assessment for risk by nursing staff at each haemodialysis treatment. Bleeding, especially from an AVF/AVG, has been the focus of work in the British Renal Society (now the UK Kidney Association) and VASBI, with the recommendations focussed on prevention of life-threatening bleeds for AVF and AVG and management when the bleed occurs (Gagan et al. 2018).

Prabhakar et al. (2015) performed a retrospective case note analysis to identify intra-dialytic complications on haemodialysis and identified the following incidence of complications:

- hypotension (26.1% of treatments)
- fever and chills (14.4%), mainly due to vascular access infection

- nausea and vomiting (14.2%)
- chest and back pain (13%)
- hypertension (10.4%)
- headache (10.4%)
- cramps (3%)
- haematoma (0.64%)

The authors highlight that incidence of complications has changed as dialysis technology has improved (Prabhakar et al. 2015). Awareness of these complications and proper prevention allows better management of these complications (Prabhakar et al. 2015).

Bray et al. (2013) performed an analysis of deaths of patients on kidney replacement therapy in Scotland. This included haemodialysis, peritoneal dialysis, and transplant patients. They identified five areas of concern for patients undergoing kidney replacement therapy:

1. prompt recognition and management of hyperkalaemia;
2. safe prescribing of medication;
3. out-of-hours care for haemodialysis patients who are often cared for by non-renal services if they have an emergency in this time period;
4. prevention and management of infection;
5. haemodialysis vascular access.

They highlighted that many of these risks occur away from the haemodialysis machine, but should still be of concern for haemodialysis patients.

Haemodialysis continues to be a high-risk treatment, with adverse events for patients quite common. Of concern include the effects of fluid removal including hypotension; vascular access problems including infection, bleeding, and problems with flows during treatment; hypoglycaemia and the problems with managing diabetes in the context of haemodialysis; machine failure and human error using this equipment; safe prescribing and administration of medications in the context of haemodialysis; out-of-hours care for haemodialysis patients with very specific needs and management of electrolyte imbalances caused either by haemodialysis or CKD. Whilst clotting of the extracorporeal circuit and associated blood loss is not highlighted as an issue, Fielding et al. (2016a) did detect some instances. Potentially this is highlighted as less of a problem, as it is monitored and managed well. However, haemodialysis nurses need to continue to monitor for this.

LESS COMMON COMPLICATIONS OF HAEMODIALYSIS

Whilst more frequent complications are important to prevent, it is still essential that the haemodialysis nurse understands the risks of rarer complications. In particular, there are a few rare complications that have catastrophic consequences for patients, but awareness can ensure they are prevented. Complications that fall into this category are haemolysis, disequilibrium syndrome, air embolism, and VND. Each complication is defined in the next sections. Figure 7.23 summarises the causes, symptoms, and management of each complication.

HAEMOLYSIS

Haemolysis is the destruction of red blood cells. This can be a particular problem on haemodialysis as causes of this can lead to mass breakdown of red blood cells. This leads to severe anaemia and hyperkalaemia, as potassium is released from destroyed red blood cells. This can be life threatening and has been known to lead to death (Rylance 2014).

DIALYSIS DISEQUILIBRIUM SYNDROME

Dialysis disequilibrium syndrome (DDS) is a phenomenon that occurs in the presence of a high urea that is decreased rapidly by dialysis (Saha and Allon 2016). The rapid reduction in urea creates an osmotic difference between the blood and brain cells, leading to fluid moving into the brain cells causing cerebral oedema (Saha and Allon 2016). However, the risk seems to be higher in the presence of metabolic acidosis, infection, and smaller body weight (Donegan and Kashani 2014; Regetia et al. 2015; Yee et al. 2016). DDS is a rare complication, but as published case studies demonstrate (Donegan and Kashani 2014; Regetia et al. 2015; Yee et al. 2016), it is still a catastrophic complication of haemodialysis.

AIR EMBOLISM

Air embolism occurs when a significant amount of air enters the circulation. As a wide bore extracorporeal circuit is utilised in haemodialysis, the risk of a life-threatening air embolism is high, although it is not known exactly what volume of air is life-threatening (Saha and Allon 2016). Current haemodialysis machines have sensitive air detectors on the venous line, to prevent infusion of air into the patient's circulation. However, there are still potential ports of entry for air on the venous line beyond the air

	Causes	Signs and Symptoms	Prevention and Management
Haemolysis	Contamination of water supplies for haemodialysis with chloramine, copper, zinc, or nitrate (Saha and Allon, 2016; Rylance, 2014) Kinking of haemodialysis tubing (Rylance, 2014) Excessively negative pressure in the extracorporeal circuit, greater than -250 mmHg Exposure of the blood to high temperatures e.g. overheated dialysate fluid (Saha and Allon, 2016)	Bright, red, frothy blood Chest pain Hyperkalaemia Anaemia Pancreatitis (Rylance, 2014)	Prevention Appropriate water systems and testing (Hoenich et al. 2016) Care when lining to prevent kinking Ensure pressure gates always active and never extended beyond -250 mmHg Haemodialysis machine monitoring of dialysate temperature Management Discontinue haemodialysis – do not washback blood Cardiac monitoring Medical review Treatment of hyperkalaemia and anaemia
Disequilibrium Syndrome	Rapid reduction of urea or rapid correction of metabolic acidosis (Saha and Allon, 2016; Yee et al. 2016; Regeti et al. 2015; Donegan and Kashani, 2014) Normally evident in acute kidney injury or new patients to haemodialysis	Nausea Vomiting Headache Disorientation Restlessness Hypertension Dizziness Seizures Coma (Saha and Allon, 2016; Regeti et al. 2015; Donegan and Kashani, 2014)	Prevention Low doses of haemodialysis limited by time and blood flow rate Slow Low Efficiency Dialysis (SLED) or haemofiltration for high-risk patients, rather than haemodialysis (Saha and Allon, 2016; Yee et al. 2016; Regeti et al. 2015) Management Discontinue haemodialysis Mannitol Critical care support for cerebral oedema (Donegan and Kashani, 2014)
Air Embolism	Inadequate priming of the	Chest pain Dysnoea	Prevention Secure connection of the

FIGURE 7.23 The rare complications of haemodialysis.

detector and between the connection to the arterial access and circuit. Due to the location of these areas of weakness, CVCs have a higher risk of air embolism. Arteriovenous access is more likely to exert a positive pressure through connections, preventing air entering any loose connections, but this is not the case with a CVC.

VENOUS NEEDLE DISLODGEEMENT (VND)

VND is a life-threatening risk to the haemodialysis patient if undetected (Rylance 2014; Rylance and Fielding 2014; Saha and Allon 2016). Dislodgement of the venous needle does not always lead to a change in venous pressure on the

	extracorporeal circuit (Saha and Allon, 2016) Loose connections on the extracorporeal circuit (Saha and Allon, 2016) Disconnection from open jugular central venous catheter.	Altered mental status Seizures Hypotension Tachycardia (Saha and Allon, 2016)	extracorporeal circuit Completion of proper priming of the extracorporeal circuit Haemodialysis machine with air detectors on the venous line Management Lie the patient head down on left-hand side Apply 100% oxygen The air embolism will either disperse over time or aspiration can be attempted (Saha and Allon, 2016)
Venous Needle Dislodgement	Inadequate taping of venous needle Insecure lines attached to the access Patient agitation (Saha and Allon, 2016)	Blood loss onto the floor Hypovolaemia Hypotension Tachycardia Anaemia	Prevention Use of butterfly taping method Visible venous access Venous pressure gates that are near to the venous pressure measurements (Saha and Allon, 2016) Blood leakage detectors placed around access (Saha and Allon, 2016) Management Replacement of lost volume of blood through blood transfusions and normal saline infusion.

FIGURE 7.23 (Continued)

machine. This means it does not trigger an alarm and the blood pump continues removing blood from the arterial needle, which is then not returned to the patient as the venous access is no longer in place.

There has been discussion about the use of blood leakage detectors to detect VND. EDTNA/ERCA has produced advice about how to prevent VND and when to use these detectors (EDTNA/ERCA 2018).

MONITORING FOR COMPLICATIONS DURING HAEMODIALYSIS

To detect and prevent common complications during haemodialysis, the following should be monitored regularly through treatment:

- blood pressure, pulse, and signs of intolerance of fluid removal;
- arterial pressure monitoring to detect vascular access flow problems and venous pressure monitoring to detect clotting within the extracorporeal circuit;
- machine functions, including fluid removal to ensure this is completed accurately;

- correct programming of the haemodialysis prescription;
- signs of infection and vascular access disconnection;
- signs and symptoms of less common complications of haemodialysis.

Vascular access should be assessed at each haemodialysis session for signs of infection and also issues indicating a risk of life-threatening bleed. U&E and FBC blood tests are normally performed and haemodialysis nurses should be aware of current results for individual patients.

On completion of treatment, haemodialysis nurses also need to ensure the patient is well enough to return home. They should ensure the patient has adequate blood pressure, is void of symptoms related to haemodialysis, the vascular access is healthy with any bleeding ceased, and haemodialysis has been completed adequately, to ensure correct correction of blood chemistry and fluid status.

MANAGEMENT OF DIABETES IN THE CONTEXT OF HAEMODIALYSIS

Diabetes is a common cause of CKD requiring dialysis (MacNeill and Ford 2017) and the management of diabetes

in the context of haemodialysis is complex (Allen and Fielding 2011; JBDS-IP 2016, Frankel et al. 2023). These patients require complex care due to a number of factors:

- Risk of hypoglycaemia in the patient with diabetes on haemodialysis (Allen and Fielding 2011; JBDS-IP 2016).
- The removal of glucose during haemodialysis and the intermittent nature of haemodialysis; interference of CKD and haemodialysis on glucose metabolism, insulin resistance, renal gluconeogenesis, and hypoglycaemia regulation. This makes use of the antidiabetic therapy complex (JBDS-IP 2016).
- The higher risk of complications from diabetes that haemodialysis patients experience – for example, diabetic foot disease (Allen and Fielding 2011; JBDS-IP 2016).
- Effect of anaemia management for end-stage kidney disease on HbA1c results (JBDS-IP 2016).
- Complex dietary needs in the context of both renal and diabetes diets (JBDS-IP 2016).
- Increased thirst due to poor glycaemic control leading to larger fluids gain in between haemodialysis sessions (JBDS-IP 2016).
- The burden of hospital and primary care appointments for the patient with diabetes managing haemodialysis thrice weekly (Allen and Fielding 2011; JBDS-IP 2016).
- Management of comorbidities across multiple specialties (Allen and Fielding 2011; JBDS-IP 2016).

Recently, to address this complexity, the Joint British Diabetes Societies for Inpatient care (JBDS-IP) have produced guidelines on managing patients with diabetes on haemodialysis (2016). These guidelines provide guidance on all aspects of management of the patient with diabetes on haemodialysis including monitoring, risks and complications, pharmacological management, prevention, and management of diabetic foot disease and dietary management. Guidelines within this document that are particularly relevant to haemodialysis nurses include the following:

- All patients with diabetes should have pre- and post-blood glucose reading.
- Patients should be educated about the risk of hypoglycaemia and be aware they are less likely to show symptoms of this.
- Patients may require different regimes to manage their diabetes on haemodialysis days.

- Patients should be encouraged to self-monitor their blood glucose levels.
- Be aware that HbA1C results are affected by anaemia control and recent transfusions and are likely to underestimate average blood glucose.
- There should be referral pathways for haemodialysis units to refer diabetic emergencies in glycaemia control, eye problems, foot problems, or cardiovascular disorders to the appropriate team for management.
- Each haemodialysis unit should have a link nurse role to the diabetes team. This link nurse should co-ordinate foot checks and escalates issues to the diabetes nurse specialist.
- Haemodialysis nursing staff should perform foot checks weekly on their patients with diabetes.
- Haemodialysis patients with diabetes with hot, swollen feet should be referred to diabetes team immediately (JBDS-IP 2016).

Allen and Fielding (2011) recommend a similar, less-structured approach. In particular, they highlight the need to manage both diabetes and renal as one disease, with joint diabetes and haemodialysis out-patient clinics and close working links between the two specialties. Given the challenges that patients with diabetes on haemodialysis experience, this approach is critical to improving the outcomes of these vulnerable patients (Allen and Fielding 2011).

PATIENT'S PERSPECTIVE OF HAEMODIALYSIS

One aspect not yet considered in this chapter is the patient's experience of haemodialysis. Whilst nurses aim to maintain the patient's lifestyle to be as healthy as possible, the burden of haemodialysis for patients and the effect on their lifestyle also needs to be considered. Whilst a lengthy life is important, quality of that life is also critical.

One study that examined patient priorities for haemodialysis is the Standardised Outcomes for Nephrology (SONG) group. This international study aims to standardise outcomes for nephrology research to allow more cohesive research that is meaningful to both patients and healthcare professionals (Tong et al. 2015). Through their approach to this work, which includes clarification of priorities from qualitative nominal groups, interviews, and Delphi technique surveys with patients, carers, and healthcare professionals (Tong et al. 2015), they have produced work that identifies what is important for haemodialysis patients and carers. The nominal group technique with patients and carers identified that their highest priorities

were those aspects that affected their ability to live a normal life (Urquhart-Second et al. 2016). Patients and carers ranked fatigue, resilience and coping, ability to travel, dialysis free time, the impact on their family, and the ability to work as important factors to them (Urquhart-Second et al. 2016). Complications were deemed as important when they had a severe or debilitating impact on their life (Urquhart-Second et al. 2016), when they affected how they lived day-to-day life through symptoms. Morton et al. (2011) identified similar findings with patient and carers' priorities around living day-to-day life and having freedom.

Whilst this perspective is understandable, healthcare professionals continue to focus on clinical outcomes over and above these priorities. The full SONG-HD study which combines patients and caregiver priorities with healthcare professionals, the highest priorities for haemodialysis research were vascular access problems, dialysis adequacy, fatigue, cardiovascular disease, and mortality (Evangelidis et al. 2017). SONG have since removed dialysis adequacy from this list and focussed on four core domains (<http://songinitiative.org/projects/song-hd>).

Within the UK, the Transforming Participation in Chronic Kidney Disease (TP-CKD) programme has developed a Patient Reported Outcome Measure (PROM) and Patient Reported Experience Measure (PREM) that was used for the first time in 2016 (Hawkins et al. 2022). This covered various aspects of kidney care, with patients rating their experiences across 38 items (Hawkins et al. 2022), and is currently used in an annual national survey in the UK. The latest survey indicates sharing decisions about care, support from the kidney team and transport, and the three lowest-scoring areas (Kidney Care UK and UK Kidney Association, 2022). This reiterates that clinical outcomes are not the only priority for good haemodialysis care.

Some studies have also examined patients' experience of vascular access. Casey et al. (2014) performed a systematic review of qualitative studies that included patients' experience of vascular access. They identified six themes to summarise the patient's experience of vascular access including heightened vulnerability caused by the vascular access and related procedures; disfigurement from the vascular access; mechanisation of the body; impinging on life; using self-preservation and ownership to cope with their vascular access and related procedures; and confronting decisions as vascular access made haemodialysis real (Casey et al. 2014). Many of the studies they examined explored patient's experience of haemodialysis, a large part of which was influenced by experiences of vascular access. Casey et al. (2014) also identified that cannulation of fistulae was an issue of concern for patients. They found patients develop a fear of needling, a dread of needling

complications, worry about unfamiliar staff needling them, and describe needling as an 'agonising invasion' of their body (Casey et al. 2014). A systematic review also summarises patient experiences of cannulation for haemodialysis demonstrating this is an unpleasant experience associated with pain, abnormal appearance, dependency, vulnerability and worry about success (Fielding et al. 2022). However, whilst cannulation for haemodialysis can be problematic for patients, experiences of AVFs are still better than TCVCs (Richarz et al. 2021; Kosa et al. 2015). Feeling safe with the person cannulating them, the technique used and the environment, and feeling in control of cannulation makes this easier for patients (Fielding et al. 2022). This highlights the importance of good cannulation skills in haemodialysis nurses. Taylor et al. (2016) found similar experiences of AVFs: patients with vascular access rely on a precarious lifeline, which is confronting, intrusive, and burdensome.

Haemodialysis nurses need to consider what will make patients' experience of haemodialysis better and what will reduce symptom burden. Nurses need to have empathy for the burden that patients experience. Whilst haemodialysis is necessary to maintain life, the burden of haemodialysis treatment and associated complications and symptoms should not be underestimated. Improving clinical outcomes will reduce this burden by reducing symptoms and complications, however we also need to consider what will make haemodialysis better for patients and their families.

CONCLUSION

The chapter commenced by examining the technical aspects of what haemodialysis is and how it works. This understanding allows considered clinical decision-making to allow haemodialysis to be tailored to the individual patient. There are many aspects of the haemodialysis treatment that can be adjusted to suit the individual. Haemodialysis nurses need to use their clinical and pragmatic viewpoint, to evaluate the findings of research, and implement those which are accurate and relevant to their patients. The nurses' role in monitoring the patient through treatment and preventing complications has been demonstrated – not just to optimise clinical outcomes but also minimise the burden that patients experience due to their chronic kidney disease and also that caused by the haemodialysis itself. Skilled and knowledgeable haemodialysis nurses are essential to optimise the patient's haemodialysis treatment improving individual patient's outcomes, symptoms, and experience to relieve the burden of haemodialysis.

REFERENCES

- Achinger, S.G., Ikizler, T.A., Bian, A., et al. (2013). Long-term effects of daily hemodialysis on vascular access outcomes. *Hemodialysis International* 17 (2): 8–15.
- Aitken E., Anijeet H., Ashby D., et al. (2023) *UK Kidney Association Clinical Practice Guideline Vascular Access for Haemodialysis*. <https://ukkidney.org/sites/renal.org/files/FINAL%20FOR%20MATTED%20Vascular%20access%20for%20haemodialysis%20April%202023.pdf> (accessed 18/10/2023).
- Al Shakarchi, J., Houston, G., and Inston, N. (2015). Early cannulation grafts for haemodialysis: a systematic review. *Journal of Vascular Access* 16 (6): 493–497.
- Allen L. and Fielding C.A. (2011). 'Haemodialysis and the Diabetic Patient' in Cruz-Casal M. and Pancirova J. (2011) *The Diabetic patient and Chronic Kidney Disease* EDTNA/ERCA.
- Almasri, J., Alsawas, M., Nainou, M. et al. (2016). Outcomes of vascular access for hemodialysis: a systematic review and meta-analysis. *Journal of Vascular Surgery* 64: 236–243.
- Ashby, D., Borman, N., Burton, J., et al. (2019). *Clinical Practice Guideline: Haemodialysis* <https://ukkidney.org/sites/renal.org/files/FINAL-HD-Guideline.pdf> (accessed 18 October, 2023).
- Aucella, F., Gesuete, A., Vigilante, M., et al. (2013). Adsorption dialysis: from physical principles to clinical applications. *Blood Purification* 35 (Supplement 2): 42–47.
- Ball, L. (2010). The buttonhole technique: strategies to reduce infections. *Nephrology Nursing Journal* 37 (5): 473–477.
- Berneih, B., Boobes, Y., Al Hakim, M.R., et al. (2009). Long-term use of low-molecular-weight heparin in hemodialysis patients: a 7-year experience. *Blood Purification* 7: 242–245.
- Blankestijn, P.J., Vernooij, R.W.M., Hackham, C., et al. for COM-VONCE scientific committee investigators (2023). Effect of hemodiafiltration or hemodialysis on mortality in kidney failure. *New England Journal of Medicine* 389: 700–709 doi: 10.1056/NEJMoa2304820.
- Booth, J., Pinney, J., and Davenport, A. (2011). Do changes in relative blood volume monitoring correlate to hemodialysis-associated hypotension? *Nephron Clinical Practice* 117: c179–c183.
- Borzou, S.R., Gholyaf, M., Zandiha, M. et al. (2009). The effect of increasing blood flow rate on dialysis adequacy in hemodialysis patients. *Saudi Journal of Kidney Disease and Transplantation* 20 (4): 639–642.
- Bramham, K., Varrier, M., Asgari, E. et al. (2008). Comparison of Tinzaparin™ and unfractionated heparin as anticoagulation on haemodialysis: equal safety, efficacy and economical parity. *Nephron Clinical Practice* 110: c107. <https://doi.org/10.1159/000158561>.
- Bray, B.D., Boyd, J., Daly, C. et al. (2013). How safe is renal replacement therapy? A national study of mortality and adverse events contributing to the death of renal replacement therapy recipients. *Nephrology Dialysis Transplantation* 29 (3): 681–687.
- Bridge, A.B. and Holt, K.E. (2015). Effect of nocturnal dialysis on prognosis in adult patients: a review of the literature. *Nephrology Nursing Journal* 42 (4): 375–379.
- BRS VA and VASBI (2018a). Clinical practice recommendations for needling of arteriovenous fistulae and grafts for haemodialysis. https://www.vasbi.org.uk/static/uploads/resources/needling_guidelines2018.pdf (accessed 18/10/2023).
- Burmeister, J.E., Campos, J.F., and Miltersteiner, D.R. (2012). Effect of different levels of glucose in the dialysate on the risk of hypoglycemia during hemodialysis in diabetic patients. *Jornal Brasileiro de Nefrologia* 34 (4): 323–327.
- Canaud, B., Bragg-Gresham, J.L., Marshall, M.R., et al. (2006). Mortality risk for patients receiving hemofiltration versus hemodialysis: European results from the DOPPS. *Kidney International* 69: 2087–2093.
- Casey, J.R., Hanson, C.S., Winkelmayer, W.C., et al. (2014). Patients' perspectives on hemodialysis vascular access: a systematic review of qualitative studies. *American Journal of Kidney Disease* 64 (6): 37–53.
- Caskey, F.J., Procter, S., MacNeill, S.J., et al. (2022). The high-volume haemodiafiltration vs high-flux haemodialysis registry trial (H4RT): a multi-centre, unblinded, randomized, parallel-group, superiority study to compare the effectiveness and cost-effectiveness of high-volume haemodiafiltration and high-flux haemodialysis in people with kidney failure on maintenance dialysis using linkage to routine healthcare databases for outcomes *Trial* 23:532. doi:10.1186/s13063-022-06357-y
- Cavanaugh, K.L., Wingard, R.L., Hakim, R.M. et al. (2009). Patient dialysis knowledge is associated with permanent arteriovenous access use in chronic hemodialysis. *Clinical Journals of the American Society of Nephrologists* 4: 950–956.
- Chang, K.Y., Kim, S.H., Kim, Y.O. et al. (2016). The impact of blood flow rate during hemodialysis on all-cause mortality. *Korean Journal of Internal Medicine* 31 (6): 1131–1139.
- Chapdelaine, I., Mostovaya, I.M., Blankestijn, P.J. et al. (2014). Treatment policy rather than patient characteristics determines convection volume in online post-dilution hemodiafiltration. *Blood Purification* 7: 229–237.
- Charra, B., Calemard, E., Ruffet, M. et al. (1992). Survival as an Index of Adequacy of Dialysis. *Kidney International* 41 (5): 1286–1291.
- Chong, B.H. (2003). Heparin-induced thrombocytopenia. *Journal of Thrombosis and Haemostasis* 1: 1471–1478.
- Chow, J., Rayment, G., San Miguel, S. et al. (2011). A randomised controlled trial of buttonhole cannulation for the prevention of fistula access complications. *Journal of Renal Care* 37 (2): 85–93.
- Cioni, L., Pamarini, D., Pilone, N. et al. (1984). Haemodiafiltration: better efficiency with respect to haemodialysis and hemofiltration. *Blood Purification* 2: 30–35.
- Clark, J.A., Schulman, G., and Golper, T.A. (2008). Safety and efficacy of regional citrate anti coagulation during 8 hour sustained

- low-efficiency dialysis. *Clinical Journal for American Society of Nephrologists* 3 (3): 736–742.
- Clark, W.R. and Gao, D. (2002). Properties of membranes used for hemodialysis therapy. *Seminars in Dialysis* 15 (1): 191–195.
- Clark, W.R., Hamburger, R.J., and Lysaght, M.J. (1999). Effect of membrane composition and structure on solute removal and biocompatibility in hemodialysis. *Kidney International* 56: 2005–2015.
- Davenport, A. (2006). Intradialytic complications during hemodialysis. *Hemodialysis International* 10: 162–167.
- Davenport, A. (2009a). Can advances in hemodialysis machine technology prevent intradialytic hypotension? *Seminars in Dialysis* 22 (3): 231–236.
- Davenport, A. (2009b). Review article: low-molecular-weight heparin as an alternative anticoagulant to unfractionated heparin for routine outpatient haemodialysis treatments. *Nephrology* 14: 455–461.
- Davies S.J., Caskey F.J., Coyle D., Lindley E., MacDonaold J., Mitra S., Wilkie M., Davenport A., Farrington K., Dasgupta I., Ormandy P., Andronis L., Solis-Trapala I. and Sim J. (2017). Rationale and design of BISTRO: a randomized controlled trial to determine whether bioimpedance spectroscopy-guided fluid management maintains residual kidney function in incident haemodialysis patients *BMC Nephrology* 18 (138) doi: 10.1186/s12882-017-0554-1
- Demirci, M.S., Celik, G., Ozkahya, M. et al. (2012). Effects of thrice weekly nocturnal hemodialysis on arterial stiffness. *Atherosclerosis* 220 (2): 477–485.
- van der Sande, F.M., Wystrychowski, G. et al. (2009). Control of core temperature and blood pressure stability during hemodialysis. *Clinical Journal of the American Society of Nephrologists* 4 (1): 93–98.
- Donegan, D. and Kashani, K. (2014). Dialysis disequilibrium syndrome: a swell diagnosis? *Journal of Medical Cases* 5 (8): 437–440.
- Dunlop, J.L., Vandal, A.C., and Marshall, M.R. (2019). Low Dialysate Sodium Levels for Chronic Haemodialysis *Cochrane Database of Systematic Reviews* CD011204. doi: 10.1002/14651858.CD011204.pub2
- EDTNA/ERCA (2028). Venous needle dislodgement. <https://edtnaerca.org/collaboration/projects-vnd#1537949556329> (accessed 11 February 2024).
- Evangelidis, N., Tong, A., Manns, B. et al. (2017). Developing a set of core outcomes for trials in hemodialysis: an international Delphi survey. *American Journal of Kidney Disease* 70 (4): 464–475.
- Ferroni, A., Gaudin, F., Guiffant, G. (2014). Pulsative flushing as a strategy to prevent bacterial colonization of vascular access devices. *Medical Devices (Auckland)* 7: 379–383.
- Fielding, C.A., Bramley, L., Stalker, C., et al. (2022). Patients' experiences of cannulation of arteriovenous access for haemodialysis: a qualitative systematic review. *Journal of Vascular Access* IN PRESS doi: 10.1177/11297298211067630
- Fielding, C.A., Rhodes, C., Chesteron, L. et al. (2016a). Development of a trigger tool to detect harm during haemodialysis. *Journal of Kidney Care* 1 (2): 72–77.
- Fielding, C.A., Cain, P., Debling, P., et al. (2016b). Clinical practice recommendations for the use of buttonhole cannulation. *Journal of Kidney Care* 1 (4): 186–193.
- Fielding, C.A., Glover, S., and Kumwenda, M. (2016c). Vascular access special interest group: a multiprofessional initiative. *Journal of Kidney Care* 1 (3): 150–152.
- Fielding, C., Spooner, H., and Aitken M. (2018). Cannulation of arteriovenous fistulae and grafts for dialysis. *Journal of Kidney Care* 3(2): 74–83.
- Fotheringham, J., Saijad, A., Stel, V.S., et al. (2019). The association between longer haemodialysis treatment times and hospitalization and mortality after the two-day break in individuals receiving three times a week haemodialysis *Nephrology Dialysis and Transplantation* 34 (9): 1577–1584. doi: 10.1093/ndt/gfz007
- Fotheringham, J., Barnes, T., Dunn, L., et al. (2021). A break-through series collaborative to increase patient participation with hemodialysis tasks: A stepped wedge cluster randomised controlled trial. *PLoS One* 16 (7): e0253966 doi:10.1371/journal.pone.0253966
- Fotherington, J., Barnes, T., Dunn, L. et al. (2017). Rationale and design for SHAREHD: a quality improvement collaborative to scale up Shared Haemodialysis Care for patients on centre based haemodialysis. *BMC Nephrology* 18: 335. <https://doi.org/10.1186/s12882-017-0748-6>.
- Frankel, A., Hussain, S., Chowdhury, T., et al. (n.d.). *Standards of Care for Glycaemic Assessment in People with Diabetes on Haemodialysis* https://abcd.care/sites/default/files/site_uploads/Resources/Position-Papers/ABCD-Guidance-Glycaemic-assessment-in-people-with-diabetes-v1.pdf (accessed 18/10/2023).
- Friesen, T., Jassal, D.S., Zhu, M. et al. (2015). Cardiovascular remodeling during long-term nocturnal home hemodialysis. *Clinical and Experimental Nephrology* 19 (3): 514–520.
- Fulker, D., Simmons, A., and Barber, T. (2017). Computational model of the arterial and venous needle during hemodialysis. *Journal of Biochemical Engineering* 139: <https://doi.org/10.1115/1.4034429>.
- Gagan A., Glover S., and Gibbs P. (2018). Managing a life-threatening bleed project. *Journal of Kidney Care* 3 (5): 312–313.
- Godelieve, A.G. (2015). Flushing and locking of venous catheters: available evidence and evidence deficit. *Nursing Research and Practice* <https://doi.org/10.1155/2015/985686>.
- Goodkin, D.A., Pisoni, R.L., Locatelli, F. et al. (2010). Hemodialysis vascular access training and practices are key to improved access outcomes. *American Journal of Kidney Disease* 56 (6): 1032–1042.
- Grudzinski, A., Mendelssohn, D., Pierratos, A. et al. (2013). A systematic review of buttonhole cannulation practices and outcomes. *Seminars in Dialysis* 26 (4): 465–475.
- Hall, Y.N., Larive, B., Painter, P. et al. (2012). Effects of six versus three times per week hemodialysis in physical performance, health and functioning: Frequent Hemodialysis Network (FHN) randomized trial. *Clinical Journal of the American Society of Nephrologists* 7 (5): 782–794.

- Harwood, L.E., Wilson, B.M., and Oudshoorn, A. (2016). Improving vascular access outcomes: attributes of arteriovenous fistula cannulation success. *Clinical Kidney Journal* 9 (2): 303–309.
- Hauk, M., Kuhlmann, M.K., Riegel, W. et al. (2000). In vivo effects of dialysate flow rate on Kt/V in maintenance hemodialysis patients. *American Journal of Kidney Diseases* 35 (1): 105–111.
- Hawkins, J., Wellsted, D., Corps, C., et al. (2022). Measuring patients' experience with renal services in the UK: development and validation of the Kidney PREM. *Nephrology Dialysis Transplantation* 37: 1507–1519 doi:10.1093/ndt/gfac030
- Held, P.J., Port, F.K., Wolfe, R.A. et al. (1996). The dose of hemodialysis and patient mortality. *Kidney International* 50 (2): 550–556.
- Henderson, L.W., Colton, C.K., and Ford, C.A. (1975). Kinetics of haemodiafiltration II. Clinical characterization of a new blood cleansing modality. *The Journal of Laboratory and Clinical Medicine* 85 (3): 372–391.
- Hoenich N., Mactier R., Morgan I., et al. (2016). Guideline on water treatment systems, dialysis water and dialysis fluid quality for haemodialysis and related therapies. Renal Association.
- Hoy, S.M., Scott, L.J., and Plosker, G.L. (2010). Tinzaparin sodium: a review of its use in the prevention and treatment of deep vein thrombosis and pulmonary embolism, and in the prevention of clotting in the extracorporeal circuit during haemodialysis. *Adis Drug Evaluation* 10: 1319–1347.
- Hull, K.L., Branham, K., Brookes, C.L., et al. (2023) The NightLife study — the clinical and cost-effectiveness of thrice-weekly, extended, in-centre nocturnal haemodialysis versus daytime haemodialysis using a mixed methods approach: study protocol for a randomized controlled trial *Trials* 24 (522) doi: 10.1186/s13063-023-07565-w.
- Hull, K.L., March, D.S., Churchward, D.R., et al. (2020). The effect of extended-hours hemodialysis on outcomes: A systematic review and meta-analysis *Haemodialysis International* 24 (2): 133–147 doi: 10.1111/hdi.12828.
- Humes, H.D., Fissell, W.H., and Tiranathangul, K. (2006). The future of hemodialysis membranes. *Kidney International* 69: 1115–1119.
- Innes, A., Charra, B., Burden, R.P. et al. (1999). The effect of long, slow haemodialysis on patient survival. *Nephrology Dialysis Transplantation* 4 (1): 919–922.
- Jaffer, Y., Selby, N.M., Taal, M.W., et al. (2008). A meta-analysis of hemodialysis catheter locking solutions in the prevention of catheter-related infection. *American Journal of Kidney Disease* 51 (2): 233–241.
- Jefferies, H.J., Virk, B., Schiller, B., et al. (2011). Frequent hemodialysis schedules are associated with reduced levels of dialysis-induced cardiac injury (myocardial stunning). *Clinical Journal of the American Society of Nephrology* 6 (6): 1326–1332.
- Joint British Diabetes Societies for Inpatient care (JBDS-IP) (2016). Management of adults with diabetes on the haemodialysis unit. <https://renal.org/wp-content/uploads/2017/07/jbds-ip-management-of-adults-with-diabetes-on-the-haemodialysis-unit-1.pdf>.
- Karaboyas, A., Zee, J., Brunelli, S.M. et al. (2017). Dialysate potassium, serum potassium, mortality, and arrhythmia events in hemodialysis: results from the Dialysis Outcomes and Practice Patterns Study (DOPPS). *American Journal of Kidney Disease* 69 (2): 266–277.
- Karet Frankl, F.E., Caward, R.J., Gallagher, H., et al. (2016). UK Renal Research Strategy <http://www.kidneyresearchuk.org/research/ukrcr>.
- Kaysen, G.A., Greene, T., Larive, B. et al. (2012). The effect of frequent hemodialysis on nutrition and body composition: frequent hemodialysis network trial. *Kidney International* 82: 90–99.
- Kidney Care UK and UK Kidney (2022). *Patient Reported Experience of Kidney Care in the UK 2021* <https://ukkidney.org/sites/renal.org/files/PREM%20report%202021.pdf> (accessed 26/02/2023).
- Kirsch, A.H., Lyko, R., Nilsson, L.G. et al. (2016). Performance of hemodialysis with novel medium cut-off dialyzers. *Nephrology Dialysis Transplantation* 32: 165–172. <https://doi.org/10.1093/ndt/gfw310>.
- Koens, M.J.W., Krasznai, A.G., Hanssen, A.E.J., et al. (2015). Vascular replacement using a layered elastin-collagen vascular graft in a porcine model: one week patency versus one month occlusion. *Organogenesis* 11 (3): 105–121.
- Kohlne, W., Sprenger, K., Spohn, B., et al. (1979). Hemodiafiltration using readily available equipment. *Journal of Dialysis* 3 (1): 27–39.
- Kosa, S.D., Bhola, C., and Lok, C.E. (2015). Measuring patient satisfaction with vascular access: vascular access questionnaire development and reliability testing. *Journal of Vascular Access* 16 (3): 200–205.
- KQuIP (2024). KQuIP: Dialysis at yours: Life fulfilled (DAYLife). <https://ukkidney.org/kquip/projects/day-life> (accessed 29 January 2024).
- Kronung, G. (1984). Plastic deformation of Cimino fistula by repeated puncture. *Dialysis and Transplantation* 13 (10): 635–638.
- Kumwenda, M., Gagen, A., and Fielding, C.A. (2017). National survey of the provision of vascular access service for haemodialysis in the UK. *Journal of Kidney Care* 2 (6): 302–307.
- Kumwenda, M., Mitra, S., and Reid, C. et al. (2015). Vascular access for haemodialysis. *UK Renal Association Clinical Practice*. www.renal.org.
- Labriola, L., Crott, R., Desmet, C., et al. (2011). Infectious complications following conversion to buttonhole cannulation of native arteriovenous fistulas: a quality improvement report. *American Journal of Kidney Disease* 57 (3): 442–448.
- Lambie, S.H., Taal, M.W., Fluck, R.J., et al. (2004). Analysis of factors associated with variability in haemodialysis adequacy. *Nephrology Dialysis Transplantation* 19: 406–412.
- Lockridge, R.S. and Kjellstrand, C.M. (2011). Nightly home haemodialysis: outcomes and factors associated with survival. *Haemodialysis International* 15 (2): 211–218.
- van Loon, M.M., Goovarts, T., Kessels, A.G.H., et al. (2010). Buttonhole needling of haemodialysis arteriovenous fistulae results in less complications and interventions compared to the rope-ladder technique. *Nephrology Dialysis Transplantation* 25: 225–230.

- Loud F. and Gallagher H. (2013). Kidney health: Delivering excellence kidney alliance. <http://www.kidneyresearchuk.org/file/media/Kidney-Health-Delivering-Excellence-1709-15-Oct.pdf>
- Loveday, H.P., Wilson, J.A., Pratt, R.J., et al. (2014). epic3: national evidence-based guidelines for preventing healthcare-associated infections in NHS hospitals in England. *Journal of Hospital Infection* 86 (Supplement 1): S1–S70.
- MacNeill, S., and Ford, D. (2017). UK Renal Registry 19th annual report: Chapter 2 UK renal replacement therapy prevalence in 2015: national and centre-specific analyses. *Nephron* 137 (suppl1): 4–72.
- MacRae, J.M., Ahmed, S.B., Atkar, R. et al. (2012). A randomised trial comparing buttonhole with rope ladder needling in conventional haemodialysis patients. *Clinical Journal American Society of Nephrologists* 7: 1632–1638.
- Mactier, R., Hoenich, N., and Breen, C. (2011). Renal Association clinical practice on haemodialysis. *Nephron Clinical Practice* 118 Suppl 1: 241–286.
- Maheshwari, V., Lau, T., Samavedham, L. et al. (2015). Effect of cool vs. warm dialysate on toxin removal: rationale and study design. *BMC Nephrology* 16 (25): <https://doi.org/10.1186/s12882-015-0017-5>.
- McCarthy, K., Sturt, J., and Adams, A. (2015). Types of vicarious learning experienced by pre-dialysis patients. *SAGE Open Medicine* <https://doi.org/10.1177/2050312115580403>.
- McCausland, F.R. and Waiker, S.S. (2014). Optimal dialysate sodium – what is the evidence? *Seminars in Dialysis* 27 (2): 128–134.
- McIntyre, C.W. (2010). Haemodialysis-induced myocardial stunning in chronic kidney disease – a new aspect of cardiovascular disease. *Blood Purification* 29 (2): 105–110.
- McIntyre, C.W., Lambie, S.H., Taal, M.W. et al. (2003). Assessment of haemodialysis adequacy by ionic dialysance: intra-patient variability of delivered treatment. *Nephrology Dialysis Transplantation* 18: 559–567.
- Moissl, U., Arias-Guillén, M., Wabel, P. et al. (2013). Bioimpedance-guided fluid management in hemodialysis patients. *Clinical Journal of American Society of Nephrologists* 8 (9): 1575–1582.
- Morton, R.L., Tong, A., Webster, A.C. et al. (2011). Characteristics of dialysis important to patients and family caregivers: a mixed methods approach. *Nephrology Dialysis and Transplantation* 26: 4038–4046. <https://doi.org/10.1093/ndt/gfr177>.
- Nesrallah, G.E., Cuerden, M., Wong, J.H. et al. (2010). Staphylococcus aureus bacteremia and buttonhole cannulation: long-term safety and efficacy of mupirocin prophylaxis. *Clinical Journal of the American Society of Nephrologists* 5 (6): 1047–1053.
- Ng, L.J., Chen, F., Pisoni, R.L. et al. (2011). Hospitalization risks related to vascular access type among incident US hemodialysis patients. *Nephrology Dialysis Transplantation* 26 (11): 3659–3666.
- NICE (2002). Guidance for home compared with hospital haemodialysis for patients with end-stage renal disease. www.nice.org.uk/guidance/ta48.
- NICE (2015). The 3M Tegaderm CHG IV securement dressing for central venous and arterial catheter insertion sites www.nice.org.uk/guidance/mtg25.
- Nicholas, J., Rana, R., Spooner, H., et al. (2017). Reducing central venous stenosis by enhancing infection prevention. *Journal of Kidney Care* 2 (5): 268–275.
- Nistor, I., Palmer, S.C., Craig, J.C., et al. (2015). Haemodiafiltration, haemofiltration and haemodialysis for end-stage kidney disease. *Cochrane Database of Systematic Reviews* 20 (5): CD006258. <https://doi.org/10.1002/14651858.CD006258.pub2>.
- Nursing and Midwifery Council (2015). The Code: Professional standards of practice and behaviour for nurses and midwives www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/nmc-code.pdf
- O'Brien, F.J., Kok, H.K.T., O'Kane, C., et al. (2012). Arteriovenous fistula buttonhole cannulation technique: a retrospective analysis of infectious complications. *Clinical Kidney Journal* 5: 526–529.
- Oliver S.W., Campbell J., Kingsmore D.B., et al. (2015). Scottish Haemodialysis Vascular Access Appraisal Report: Relating Variation in Outcomes to Variation in Processes <http://www.srr.scot.nhs.uk/Projects/Projects3.html#SVAA>
- Onofriescu, M., Mardare, N.G., Segall, L., et al. (2012). Randomized trial of bioelectrical impedance analysis versus clinical criteria for guiding ultrafiltration in hemodialysis patients: effects on blood pressure, hydration status, and arterial stiffness. *International Urology and Nephrology* 44 (2): 583–591.
- Parissotto, M.T., Schoder, V.U., Miriunis, C., et al. (2014). Cannulation technique influences arteriovenous fistula and graft survival. *Kidney International* 86: 790–797.
- Parker, T.F., Husni, L., Huang, W., et al. (1994). Survival of hemodialysis patients in the United States is improved with a greater quantity of dialysis. *American Journal of Kidney Diseases* 23 (5): 670–680.
- Penne, E.L., Levin, N.W., and Kotanko, P. (2010). Improving volume status by comprehensive dietary and dialytic sodium management in chronic hemodialysis patients. *Blood Purification* 30: 71–78.
- Pergolotti, A., Rich, E., and Lock, K. (2011). The effect of the buttonhole method vs. the traditional method of AV fistula cannulation on hemostasis, needle stick pain, pre-needle stick anxiety, and presence of aneurysms in ambulatory patients on hemodialysis. *Nephrology Nursing Journal* 38 (4): 333–336.
- Poon, C.K., Tang, H.L., Wong, J.H., et al. (2015). Effect of alternate night nocturnal home hemodialysis on anemia control in patients with end-stage renal disease. *Hemodialysis International* 19 (2): 235–241.
- Port, F.K., Morgenstern, H., Bieber, B.A., et al. (2017). Understanding associations of hemodialysis practices with clinical and patient-reported outcomes: examples from the DOPPS. *Nephrology Dialysis Transplantation* 2 (Supplement 2): ii106–ii112.
- Prabhakar, S.R.G., Singh, S., Singh Rathore, S., et al. (2015). Spectrum of intradialytic complications during hemodialysis and its management: a single-center experience. *Saudi Journal Kidney Disease and Transplantation* 26 (1): 168–172.
- Ravani, P., Palmer, S.C., Oliver, M.J., et al. (2013). Associations between haemodialysis access type and clinical outcomes: a systematic review. *Journal of the American Society of Nephrology* 24: 465–473.

- Regetia, K., Jehangira, W., Kumarb, S., et al. (2015). Intermittent dialysis leading to dialysis disequilibrium syndrome. *World Journal of Nephrology and Urology* 4 (3): 247–250.
- Richarz, S., Greenwood, S., Kingsmore, D.B., et al. (2021). Validation of a vascular access specific quality of life measure (VASQoL). *Journal of Vascular Access* IN PRESS doi:10.1177/11297298211046746
- Rioux, J.P., Narayanan, R., and Chan, C.T. (2012). Caregiver burden among nocturnal home hemodialysis patients. *Hemodialysis International* 16 (2): 214–219.
- Rocco, M.V., Lockridge, R.S., Beck, G.J., et al. (2011). The Effects of frequent nocturnal home hemodialysis: the frequent hemodialysis network nocturnal trial. *Kidney International* 80 (10): 1080–1091.
- Roumelioti, M.E. and Unruh, M.L. (2015). Lower dialysate temperature in hemodialysis: is it a cool idea? *Clinical Journal of the American Society of Nephrologists* 10 (8): 1318–1320.
- Rylance, P.B. (2014). Improving patient safety and avoiding incidents in renal units. *Journal of Renal Nursing* 6 (1): 24–29.
- Rylance and Fielding (2014). What are the main risks for safety of renal patients? *British Journal of Renal Medicine* 19 (3): 23–26.
- Saha, M. and Allon, M. (2016). Diagnosis, treatment and prevention of hemodialysis emergencies. *Clinical Journal of the American Society of Nephrology* <https://doi.org/10.2215/CJN.05260516>.
- Santoro, A. and Guadagni, G. (2010). Dialysis membrane: form convection to adsorption. *NDT Plus* 3 (Supplement 1): i36–i39.
- Saran, R., Bragg-Gresham, J.L., Levin, N.W., et al. (2006). Longer treatment time and slower ultrafiltration in hemodialysis: associations with reduced mortality in the DOPPS. *Kidney International* 69: 1222–1228.
- Selby, N.M., Burton, J.O., Chesterton, L.C., et al. (2006). Dialysis-induced regional left ventricular dysfunction is ameliorated by cooling the dialysate. *Clinical Journal of the American Society of Nephrologists* 1 (6): 1216–1225.
- Selby, N.M. and McIntyre, C.W. (2006). A systematic review of the clinical effects of reducing dialysate fluid temperature. *Nephrology Dialysis Transplantation* 21 (7): 1883–1898.
- Smith, J.R., Zimmer, N., Bell, E., et al. (2017). A randomized, single, blind, crossover trial of recovery time in high-flux hemodialysis and hemodiafiltration. *American Journal of Kidney Disease* 69 (6): 762–770.
- Smyth, W., Hartig, V., and Manickam, V. (2013). Outcomes of buttonhole and rope-ladder cannulation techniques in a tropical renal service. *Journal of Renal Care* 39 (3): 157–165.
- Sombolos, K.I., Fragia, T.K., Gionanlis, L.C., et al. (2009). The anticoagulant activity of enoxaparin sodium during on-line hemodiafiltration and conventional hemodialysis. *Hemodialysis International* 13: 43–47.
- Suri, R.S., Larive, B., Sherer, S., et al. (2013). Risk of vascular access complications with frequent hemodialysis. *Journal of American Society of Nephrologists* 24 (3): 498–505.
- Tang, H.L., Wong, J.H., Poon, C.K., et al. (2011). One year experience of nocturnal home haemodialysis with an alternate night schedule in Hong Kong. *Nephrology (Carlton)* 16 (1): 57–62.
- Taylor, M.J., Hanson, C.S., Casey, J.R., et al. (2016). ‘You know your own fistula, it becomes a part of you’ – Patient perspectives on vascular access: a semi-structured interview study. *Haemodialysis International* 20 (5): 5–14.
- The FHN Trail Group (2010). In-center hemodialysis six times per week versus three times per week. *The New England Journal of Medicine* 363 (24): 2287–2300.
- Thomson, B.K., Huang, S.H., Chan, C., et al. (2014). Nocturnal home hemodialysis associates with improvement of electrocardiographic features linked to sudden cardiac death. *ASAIO Journal (American Society for Artificial Internal Organs: 1992)* 60 (1): 99–105.
- Timsit, J.F., Mimox, O., Mourvillier, B., et al. (2012). Randomized controlled trial of chlorhexidine dressing and highly adhesive dressing for preventing Catheter-related infections in critically ill adults. *American Journal of Respiratory and Critical Care Medicine* 186 (12): <https://doi.org/10.1164/rccm.201206-1038OC>.
- Tong, A., Manns, B., Hemmelgarn, B., et al. (2015). Standardised outcomes in nephrology – haemodialysis (SONG_HD): study protocol for establishing a core outcome set in haemodialysis. *Biomed Central Trials* 16: 364. <https://doi.org/10.1186/s13063-015-0895-7>.
- Tsujimoto, Y., Tsujimoto, H., Nakata, Y., et al. (2019). Dialysate temperature reduction for intradialytic hypotension for people with chronic kidney disease requiring haemodialysis. *Cochrane Database of Systematic Reviews* CD012598. doi: 10.1002/14651858.CD012598.pub2
- Twardowski, Z.J. and Kubara, H. (1979). Different sites versus constant sites of needle insertion into arteriovenous fistulas for treatment by repeated dialysis. *Dialysis and Transplantation* 8 (10): 78–80.
- Twardowski, Z.J. and Misra, M. (2010). ‘Daily’ dialysis – Lessons learned from a randomised controlled trial. *The New England Journal of Medicine* 363 (24): 2363–2364.
- UK Renal Registry (2023) *UK Renal Registry 25th Annual Report – data to 31/12/2021*, Bristol, UK. Available from <https://ukkidney.org/audit-research/annual-report>
- UKRR and BKPA (2016). Patient experience of kidney care: A report to test patient reported experience measures (PREM) in renal units in England 2016. www.thinkkidneys.nhs.uk/ckd/wp-content/uploads/sites/4/2017/07/PREM-2016-Report.pdf
- Unruh, M.L., Larive, B., Chertow, G.M. et al. (2013). Effects of 6-times-weekly versus 3-times-weekly hemodialysis on depressive symptoms and self-reported mental health: Frequent Hemodialysis Network (FHN) trials. *American Journal of Kidney Disease* 61 (5): 748–758.
- Urquhart-Second, R., Craig, J.C., Hemmelgarnd, B., et al. (2016). Patient and caregiver priorities for outcomes in hemodialysis: an international nominal group technique study. *American Journal of Kidney Disease* 68 (3): 444–454.
- Vaux, E., King, J., Lloyd, S., et al. (2013). Effect of buttonhole cannulation with a polycarbonate peg on in-center hemodialysis fistula outcomes: a randomized controlled trial. *American Journal of Kidney Disease* 62 (1): 81–88.
- Vilar, E., Fry, A., Wellsted, D., et al. (2009). Long-term outcomes in on-line hemodiafiltration and high-flux hemodialysis: a comparative

- analysis. *Clinical Journal of American Society of Nephrologists* 4 (12): 1944–1953.
- Wabel, P., Chamney, P., Moissl, U., et al. (2009). Importance of whole-body bioimpedance spectroscopy for the management of fluid balance. *Blood Purification* 27 (1): 75–80.
- Walker, R.C., Hanson, C.S., Palmer, S.C., et al. (2015). Patient and caregiver perspectives on home hemodialysis: a systematic review. *American Journal of Kidney Disease* 65 (3): 451–463.
- Warwick G., Mooney A., Russon L., et al. (2013). Planning, initiation and withdrawal of renal replacement therapy. UK Renal Association Clinical Practice Guideline. www.renal.org.
- Wilkie M. and Barnes T. (2019). Shared haemodialysis care. *Clinical Journal of American Society of Nephrology* 14 (9): 1402–1404 doi: 10.2215/CJN.02050219
- Xi, W., Singh, P.M., Harwood, L., et al. (2011). Patient experiences and preferences on short daily and nocturnal home hemodialysis. *Hemodialysis International* 17 (2): 201–207.
- Yee, M.D., Jern, Y.H., and Seng, C.W. (2016). Dialysis disequilibrium syndrome: a preventable fatal acute complication. *Medical Journal of Malaysia* 71 (2): 91–92.
- Yon, C.A. and Low, C.L. (2013). Sodium citrate 4% versus heparin as a lock solution in hemodialysis patients with central venous catheters. *American Journal of Health-System Pharmacy* 70 (2): 131–136.
- Zacharias, J.M., Weatherston, C.P., Spewark, C.R., et al. (2003). Alteplase versus Urokinase for occluded hemodialysis catheters. *Annals of Pharmacotherapy* 37 (1): 27–33.
- Zeraati, A., Mousavi, S.S.B., and Mousavi, M.B. (2013). A review article: access recirculation among end stage renal disease patients undergoing maintenance hemodialysis. *Nephro Urology Monthly* 5 (2): 728–732.
- Zhang H., Schaubel D.E., Kalbflesch J.D., et al. (2012). Dialysis outcomes and analysis of practice patterns suggests the dialysis schedule affects day-of-week mortality. *Kidney International* 81 (11): 1108–1135.

Peritoneal Dialysis

Sally Punzalan

Imperial College Healthcare NHS Trust, UK

CHAPTER 8

LEARNING OUTCOMES

- to recognise the importance of individualised care for those receiving peritoneal dialysis (PD).
- to review the anatomy and physiology of the peritoneum.
- to identify best practice for the care of the PD catheter and exit site.
- to explore the best use of each PD therapy option.
- to understand the criteria for good patient selection for PD.
- to review all factors required to adequately dialyse a patient with PD.
- to review the complications of PD.
- to understand the importance of good ongoing education for those receiving PD.

INTRODUCTION

PD as a treatment for end-stage kidney disease (ESKD) is a relatively simple and very effective technique. From its introduction in the late 1970s, PD has been refined and developed into a flexible and adaptable therapy that is the treatment of choice for many patients. PD has been found to be most effective if performed as a continuous treatment, either by the patient during the day (continuous ambulatory peritoneal dialysis [CAPD]) or by a machine, whilst the patient sleeps (automated peritoneal dialysis [APD]). Owing to its continuous nature, patients who are treated by this therapy tend to have a more stable biochemical and fluid profile. Its flexible nature makes it suitable for almost all patients with ESKD. PD used in the context of an integrated dialysis program is associated with good clinical outcomes, certainly comparable with haemodialysis (HD) in the medium term and potentially better in the first 2 years of dialysis (Woodrow et al. 2017).

This chapter discusses the importance of having individualised therapy for each patient, which is structured around both clinical and lifestyle needs. The chapter starts with an overview of the anatomy and physiology of the peritoneum and practical aspects of the therapy, and different therapy options on PD; complications and patient education and training are also discussed. As the therapy

is predominately performed by the patients themselves in their homes, the main focus is on providing patients with not only an individualised treatment but also adequate psychological and nursing care, which are essential elements for a successful therapy. The advent of assisted PD (whereby another person, who is not the patient, performs the exchanges) is now available in many centres.

PHYSIOLOGY OF PERITONEAL DIALYSIS

The peritoneal membrane, so called because it covers the abdominal cavity and is derived from the Greek word *peritonaion*, meaning 'to stretch around', has a surface area of up to 2 m². The peritoneal cavity is the potential space between the parietal membrane (which lines the abdominal cavity) and the visceral membrane (the inner layer which closely covers the organs and includes the mesenteries). Under normal circumstances, this cavity contains between 50 and 100 ml of fluid that acts as a lubricant (Figure 8.1).

During PD, physiological solution or dialysis fluid is instilled into the peritoneal cavity. Uraemic toxins and solutes move across the membrane by the process of diffusion, from the bloodstream into the dialysis fluid, or vice versa, depending on the concentration gradient. The composition of the dialysis fluid is near to that of normal extracellular fluid.

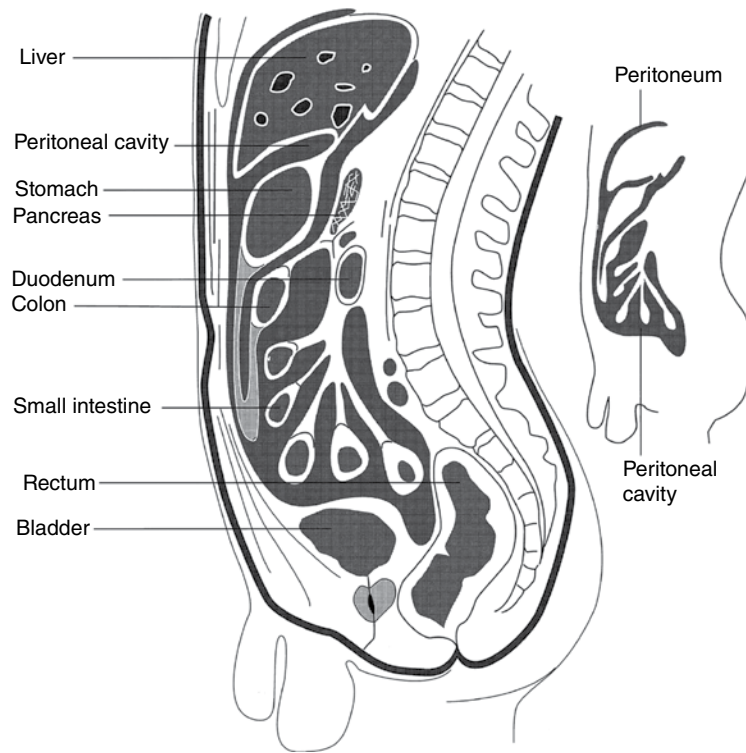


FIGURE 8.1 Location of the peritoneal cavity.

Fluid removal takes place by osmosis. The dialysis fluid is made hypertonic to plasma by the addition of osmotic agent, usually glucose. Other osmotic solutions are discussed later in this chapter.

The membrane is made up of three layers (Figure 8.2a):

1. **Mesothelium.** Underneath this lies the connective tissue. The luminal side of the mesothelium is covered with numerous microvilli that are believed to increase the surface area of the peritoneum to up to 40 m² in a healthy individual (Figure 8.2b).
2. **Peritoneal interstitium.** This is composed of fibres and bundles of collagen.
3. **Capillary endothelium.** This forms a complex branching system.

BLOOD SUPPLY

The visceral peritoneum is supplied by the superior mesenteric artery. The parietal peritoneum is supplied by the intercostal, epigastric, and lumbar arteries. Venous return from the visceral peritoneum is to the portal circulation,

whereas that from the parietal peritoneum goes into the caval circulation. This is important because it means that any drugs administered via the peritoneum will be transported to the liver, the normal route.

LYMPHATIC DRAINAGE

Lymphatic drainage from the peritoneal cavity returns excess fluid and proteins into the systemic circulation. Its other function is to remove foreign bodies from the peritoneal cavity. Lymphatic drainage is a one-way system, the flow rate of which may be affected by respiratory rate, intraperitoneal (IP) hydrostatic pressure, posture, or peritonitis.

PERITONEAL MEMBRANE TRANSPORT CHARACTERISTICS

The peritoneal membrane is semipermeable and allows the passage of both water and solutes. During PD, three processes are involved in removing fluid and wastes from the bloodstream and balancing electrolytes. These are osmosis, diffusion, and convection.

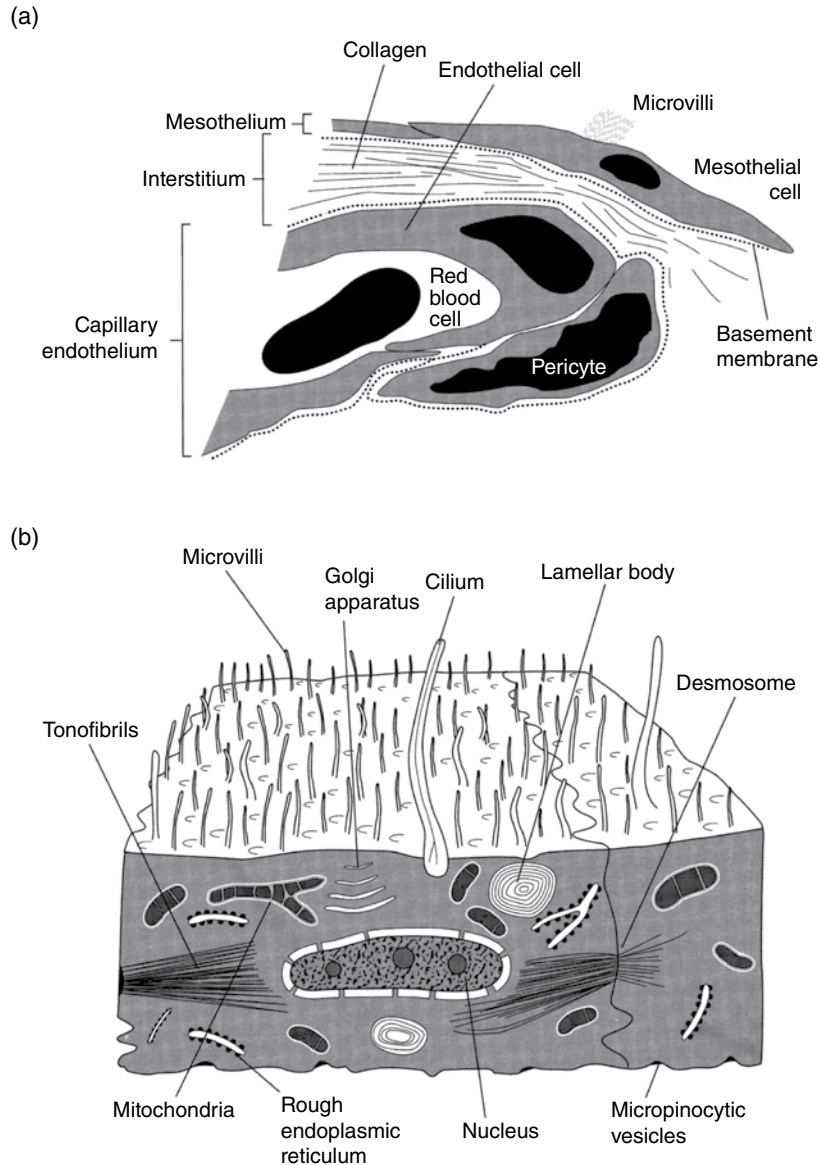


FIGURE 8.2 (a) The three layers of the peritoneal membrane. (b) Diagrammatic representation of a normal mesothelial cell.

OSMOSIS

This is the movement of water through a semipermeable membrane from a solution of low concentration into a solution with a higher concentration. The solution into which the water moves in PD contains an osmotic agent, usually glucose (other osmotic agents are discussed later in this chapter). The higher the glucose concentration, the greater the osmotic effect will be, so removing more water from the patient's bloodstream (Figure 8.3).

DIFFUSION

This is solute exchange between two solutions, usually separated by a semipermeable membrane. The solutes will travel in either direction across the membrane until equilibrium is achieved. The direction and speed at which the solutes flow depend on the concentration gradient. Solutes will flow from the stronger solution into the weaker solution (Figure 8.4). Therefore, solutes can pass in either direction across the peritoneal membrane. Other factors

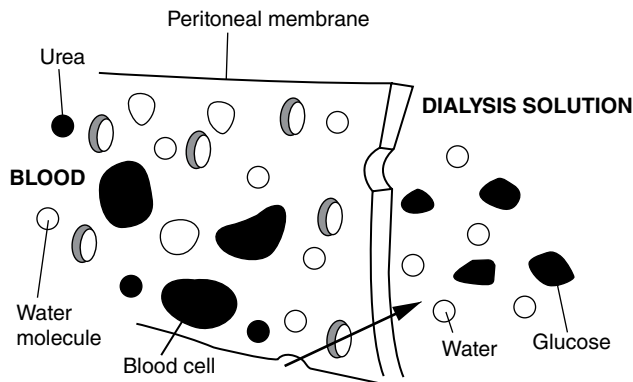


FIGURE 8.3 Osmotic ultrafiltration across the peritoneal membrane with a glucose dialysis solution in the peritoneal cavity.

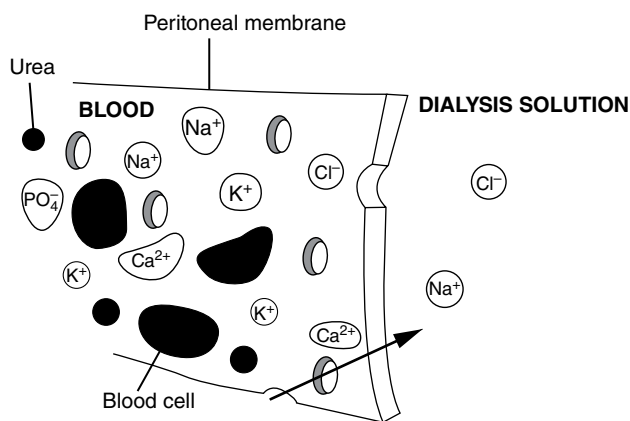


FIGURE 8.4 The peritoneum acts as a semipermeable membrane, allowing small solutes and water to diffuse through, but retaining large particles such as blood cells.

that affect diffusion rate are molecular weight and membrane resistance.

Molecular weight

Diffusion is a spontaneous process whereby solutes move randomly. Lighter, smaller molecules will move quicker than larger, heavier molecules. Urea (which has a molecular weight of 60 Da) diffuses from blood to dialysate more rapidly than creatinine (molecular weight 113 Da) or vitamin B₁₂ (molecular weight 1352 Da). Unlike HD, where the membrane pore size is controlled, the peritoneal membrane allows transport of large molecules and even proteins. Protein transport into the dialysate is unfortunate as this is an essential nutrient, particularly in dialysis patients who may be catabolic.

Membrane resistance

The permeability of the individual's membrane is an important factor controlling diffusion of solutes. Measurement of this is discussed later in this section.

A patient's peritoneal permeability may be changed during illness. Acute episodes of peritonitis appear to greatly increase the membrane permeability to both solutes and water. However, fibrotic thickening of the membrane may lead to a severe reduction in its permeability. Further reading on the functional structure of the peritoneum can be found in Gotloib (2009).

CONVECTION

Owing to the large amount of osmotic ultrafiltration (UF) that takes place during PD, convective flow transports or 'drags' water and solutes across the membrane. This occurs at a much faster rate than that which may be accounted for by diffusion alone.

The ability of glucose to exert an effective osmotic pressure depends on its ability to stay in solution in the dialysate. If the peritoneal membrane were perfectly semipermeable (i.e. only permeable to water), the osmotic pressure would be maximised. However, the peritoneum is permeable to solutes as well as water, and therefore allows the glucose through. The osmotic gradient is therefore maximum at the beginning of the exchange. The UF will decrease during the dwell time as glucose is absorbed into the bloodstream. It is estimated that UF is maximised at the beginning of the PD fluid exchange when the concentration gradient is highest. The total dialysate and ultrafiltrate volume continue to decrease after this point due to lymphatic absorption (Lokesh and Arun Kumar 2013).

MEASUREMENT OF PERITONEAL PERMEABILITY

The characteristics, pore size, and dimensions of the peritoneal membrane do not come printed on the side of a packet as they do in HD. It is therefore important to determine the characteristics of the patient's peritoneal membrane before an appropriate prescription can be written. A number of methods have been described, including standardised peritoneal assessment (SPA), the Peritoneal Equilibrium Test (PET) including Fast or mini-PET, Personal Dialysis Capacity (PDC) test, and more recently double mini PETs. The PET is the most commonly used.

The PET was described in 1987 by Twardowski et al. and determines solute transport rates over time and the UF capacity of the membrane. The results of the test can therefore be used to determine the optimum length of time that

PD fluid should be left inside the peritoneal cavity to gain maximum fluid and solute removal. It also alerts the practitioner to any changes in membrane function that could affect patient's dialysis adequacy and outcomes. A review of evaluation methods of peritoneal membrane characteristics has been written (Van Biesen et al. 2010). Recent International Society of Peritoneal Dialysis (ISPD) guidelines focus on evaluating dysfunction of an adult's peritoneal membrane as this may be used to change the PD prescription to achieve the best outcomes (Morelle et al. 2021).

PERFORMING A PET

The PET test was traditionally carried out by an experienced PD nurse in a clinic environment; however, with the adoption of the 'fast' PET where blood samples are taken at four hours only (Akdam et al. 2014) this can now be performed at home, allowing for greater flexibility. Prior to performing the test, the patient's PD catheter function should be checked so that poor drainage due to mechanical problems with the catheter (such as constipation) are not attributed to membrane function. In addition, patients should be normally hydrated, and patients with diabetes should have serum glucose levels within normal limits. This enables the results of the test to be interpreted accurately.

To enable accurate reproduction of the test according to Twardowski's original work, the following is the original protocol, which is the basis for all tests and should be used if there is any doubt over the reliability of the 'fast' or modified PET:

1. The patient attends the clinic with a 2.27% bag, which has dwelled in the peritoneum for 8–12 hours. This is drained out, the volume and dwell time recorded, and a sample taken.
2. The patient is then instilled with another bag of 2.27%. The volume should be the same as the overnight bag but ideally no smaller than 2000 ml.
3. This is drained in over 10 minutes with the patient in a supine position, rolling from side to side to ensure mixing whilst the fluid is infused.
4. Dialysate samples are taken at 0, 2, and 4 hours with a serum sample at 2 hours.
5. It is essential to record the drain-out time and the drain-out volume at 4 hours to assess the UF capacity of the membrane.
6. Finally, the patient's usual PD solution is instilled before going home.

7. The samples are then sent for analysis of glucose and creatinine levels as soon as possible.

Calculating results

In order to determine the patient's membrane solute transport characteristics, the level of creatinine that is in the PD fluid at 0, 2, and 4 hours is compared with the level of creatinine in the patient's plasma (D/P ratio). This gives a ratio of between 0 and 1. The closer the dialysate-to-plasma ratio is to 1, the faster solutes equilibrate across the membrane. Glucose absorption, from the PD solution into the patient's serum, is calculated in the same way. The level of glucose in the PD fluid at 0, 2, and 4 hours is compared with the level in the patient's serum (D/P ratio). The closer the ratio is to 1, the faster glucose crosses the membrane. Patients who equilibrate solutes fast will therefore have good solute removal during PD; however, as glucose will also be absorbed quicker, the glucose concentration gradient will not be sustained. Thus, fluid removal will be poor. The results can be plotted to determine the transporter status of the peritoneum.

The most common problem with the peritoneal membrane occurs when fluid is not removed as well as it should be. This happens when toxins in the blood cross the membrane more quickly than they should. This is referred to as a fast peritoneal solute transfer rate (PSTR). Since more efficient fluid removal is associated with better outcomes, developing a personal PD prescription based on the person's PSTR is critically important.

Figure 8.5 provides an overview on how to evaluate Peritoneal Membrane Dysfunction in adults.

The UK Renal Association (now the UK Kidney Association) (Woodrow et al. 2017) has recommended that repeat PET tests should be routinely performed 6 weeks after commencing PD and at least annually or when clinically indicated – for example, if problems arise such as an apparent loss of UF or if there is a change in therapy such as transfer from CAPD to APD. Changes over time in the test results can then be related to clinical performance and treatment regimens may be altered accordingly.

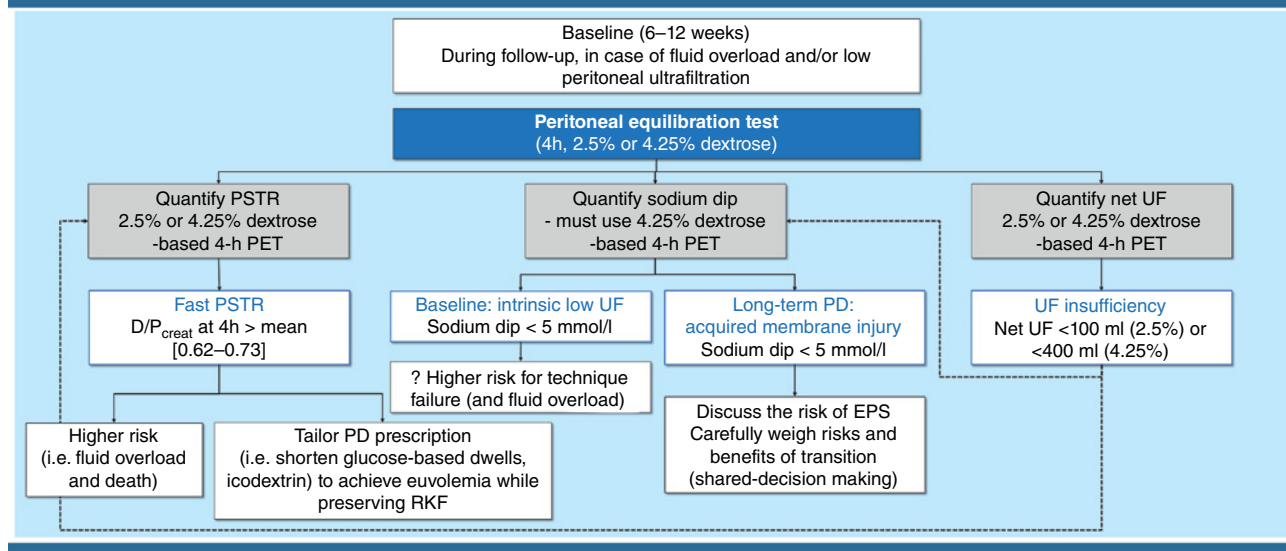
Analysis of results

When the patient's transport characteristics have been identified, it is easy to tailor the treatment to suit the membrane. Patients who have high transport membranes should have rapid exchanges of fluid, usually achieved by using APD. Patients who transport glucose and solutes more slowly are better suited to receiving CAPD where the fluid remains in the peritoneal cavity for longer periods. Any prescription modification should be accompanied by an assessment of the

ISPD Recommendations for the Evaluation of Peritoneal Membrane Dysfunction in Adults



PERITONEAL
DIALYSIS
INTERNATIONAL



Johann Morelle, Joanna Stachowska-Pietka, Carl Oberg, et al. **ISPD recommendations for the evaluation of peritoneal membrane dysfunction in adults: Classification, measurement, interpretation and rationale for intervention.** <https://doi.org/10.1177/0896860820982218>

FIGURE 8.5 Evaluation of Peritoneal Membrane Dysfunction.

patient's lifestyle to ensure that the treatment is achievable within work and social constraints. By performing this test regularly, it is possible to monitor peritoneal membrane function over time and therefore diagnose acute membrane injury, inadequate UF, and poor solute clearance.

PERITONEAL DIALYSIS ACCESS AND EXIT SITE CARE

Despite PD catheter insertion being a relatively simple procedure, the implications of getting it wrong can be catastrophic for the patient at a most vulnerable time. Not only can poor insertion technique lead to a malfunctioning catheter, it can also be responsible for infection and PD failure.

There are many facets to successful PD access:

- choosing the right catheter type and length;
- good insertion technique;
- meticulous pre-operative and post-operative care.

However, what is fundamental is effective teamwork from the multidisciplinary team, in particular the medical and nursing staff.

TYPES OF CATHETERS

The perfect PD catheter is one that provides reliable and rapid inflow and outflow from the peritoneal cavity without leaks or infections. Catheters should be designed to stay in the pelvic cavity and be easy to insert.

PD catheters generally have three portions (Figure 8.6):

1. *Outer segment.* This connects via an adapter to the solution transfer set.
2. *Intramural segment.* This has Dacron cuffs, spaced about 8 cm apart. By creating an inflammatory response, fibrous tissue fixes the catheter into position, thereby minimising leakage of dialysate and preventing bacteria entering the catheter 'tunnel' and intraperitoneal segment.
3. *IP section.* This has many small holes up the side, is situated inside the peritoneal cavity for the in- and outflow of the solution.

Variations in the design of catheters include the number of cuffs (one versus two), the design of the intramural segment (permanently bent versus straight), and the IP portion (straight versus curled). Despite the number of

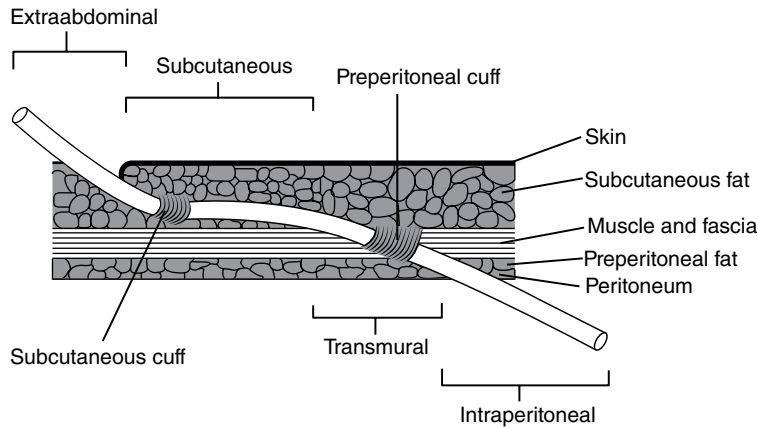


FIGURE 8.6 Functional parts of the peritoneal catheter.

types of catheters available, the most widely used are the straight (Figure 8.7) and curled (Figure 8.8) Tenckhoff catheters. They are easily inserted under local or general anaesthetic and choice of catheter will usually depend on local preference.

Another option, the Swan-neck (Figure 8.9) catheter, was developed to aid outflow of the dialysate. With two downward-pointing segments, migration of this type of catheter is rare thereby serving to aid outflow. It is also thought to prevent infections at the exit site as this segment of the catheter also points downwards, thus preventing accumulation of sweat and pus.

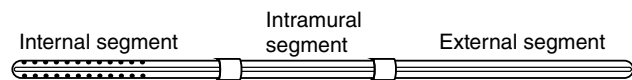


FIGURE 8.7 Straight Tenckhoff catheter.

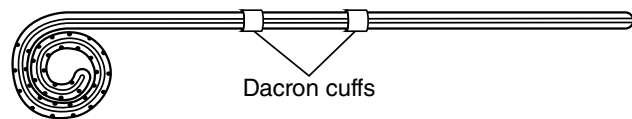


FIGURE 8.8 Curled Tenckhoff catheter.

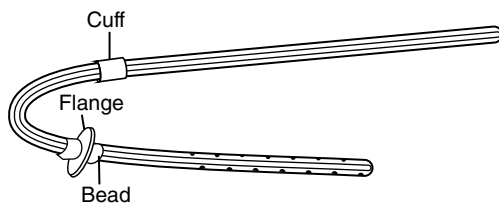


FIGURE 8.9 Swan-neck catheter.

There appears to be no difference in peritonitis rates based on the number of cuffs; however, the adoption of prophylactic exit-site and intranasal antibiotics may have reduced exit-site colonization and infection sufficiently that the benefit of a double cuff may be important when these prophylactic antibiotics are not used (Crabtree et al. 2019).

PRE-INSERTION PREPARATION OF THE PATIENT

A full pre-operative assessment of the patient is essential to identify existing or potential hernias. If present these can be repaired during the catheter insertion. The catheter exit site should be determined before the catheter is inserted. The preferred site should first be discussed with the patient to help promote participation in and an understanding of the therapy. The following points should be followed when determining the exit site of the patient's catheter:

- The site should be determined whilst the patient is in a relaxed sitting or standing position.
- It should be either above or below the belt line, whichever the patient prefers.
- Skin folds and abdominal scars should be avoided.
- The catheter exit site should be located where the patient can effectively carry out exit-site care.
- Once the exit site has been determined, it should be marked clearly with a permanent skin marker.

The patient's lifestyle, work, and hobbies should be taken into consideration when placing the catheter.

PREOPERATIVE CARE OF THE PATIENT

On the morning of the operation, the patient should bathe or have a shower. If necessary, abdominal hair should be clipped. A major cause of catheter failure, particularly at the start of PD, is constipation, and it is therefore recommended that a powerful aperient such as PicoLax is given the day before catheter insertion. It is also important that the patient has an empty bladder before the insertion procedure takes place. Other usual pre-operative practices should also be followed.

Staphylococcus Aureus Screening

There is evidence (Piraino et al. 2005) that patients who have nasal carriage of *S. aureus* have an increased risk of exit site infection and peritonitis, and that the use of Mupirocin cream or ointment at the exit site can reduce the incidence of infection. It is therefore advisable to screen all

patients for *S. aureus* prior to catheter insertion and treat accordingly.

Prophylactic antibiotics

There is evidence that prophylactic antibiotics prevent catheter infections and peritonitis (Galallah et al. 2000). Recent guidelines still recommend that prophylactic antibiotics should be administered at the time of catheter insertion (Piraino et al. 2005).

Psychological preparation of the patient

This is of absolute importance for someone who is new to PD, and this is discussed in detail in Chapter 4.

Insertion techniques

PD is a life-maintaining therapy. Access to the peritoneal cavity, via the PD catheter, is therefore particularly important in ensuring its success (see Figure 8.10 for the

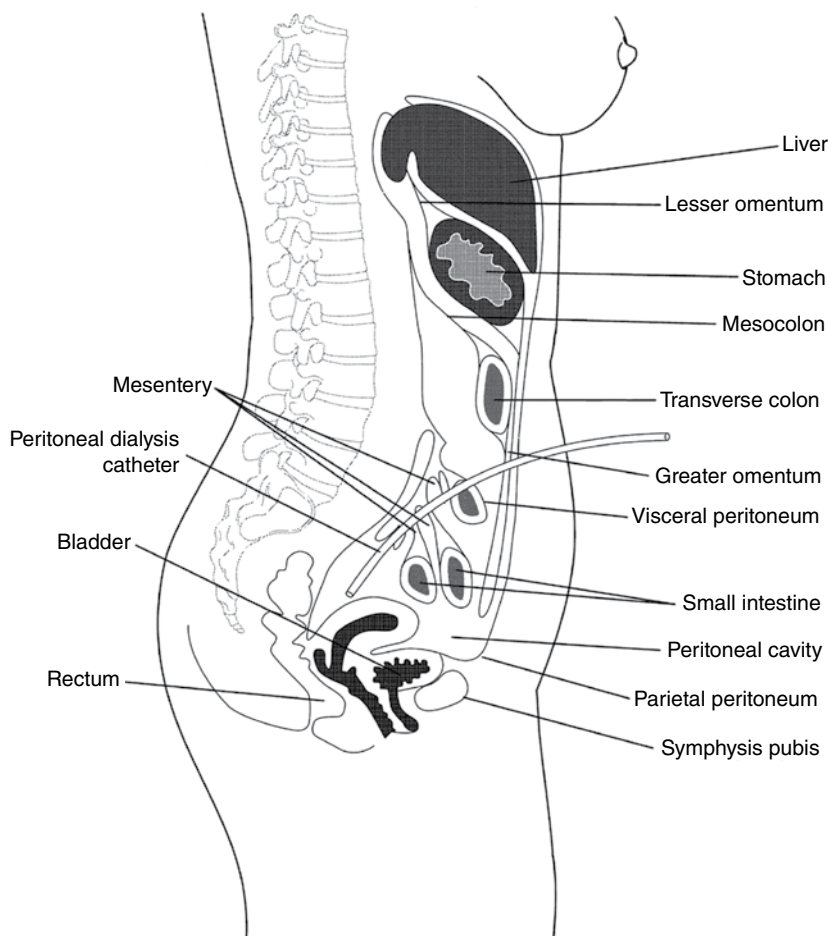


FIGURE 8.10 The position of a peritoneal dialysis catheter in the abdomen.

correct position of the catheter in the abdomen). The insertion technique should be treated as a skill acquired by experienced surgeons, physicians, and specialist nurses, rather like implantation of a pacemaker or similar device. A team approach is essential and nurse involvement is most important. The nurse's role in insertion of PD catheters starts with the pre-operative preparation described in the previous section, all of which can be carried out by the nurse. In many centres the PD nurse accompanies the patient to the operating theatre or procedures room to ensure correct procedures are carried out and that the catheter is functioning well before final wound closure is made.

As shown in Table 8.1, PD catheter implementation choices are based on patient factors, facility resources, and operator expertise (Crabtree et al. 2019).

PERIOPERATIVE CARE OF THE PATIENT

For management of the catheter in the perioperative period, and catheter-related problems including leak (internal and external), poor flow, obstruction, and hernias, the guidelines developed by the ISPD should be followed (ISPD 2023). Catheter problems such as leaks, hernias, and prolapse are an important medical indication for the use of APD either temporarily or permanently; poor flow or catheter-related flow pain should be treated with tidal APD. In the majority of cases where surgical repair for mechanical complications is required (e.g. catheter replacement, hernia repair), it is possible to avoid using a temporary HD. In many patients, remaining residual renal function (RRF) may permit an adequate period post-surgery before dialysis needs to be recommenced. Where PD does need to start soon after surgery, in many cases this may be safely achieved by initial use of APD

with small volume exchanges and avoiding a day dwell in ambulant patients (Woodrow et al. 2017).

POST-OPERATIVE CARE OF THE PATIENT

There are three main goals of post-operative catheter care:

1. Minimise any bacterial colonisation of the exit site and tunnel during the early healing period.
2. Prevent trauma to the exit site and traction on the cuffs by immobilisation of the catheter.
3. Minimise intra-abdominal pressure to prevent leakage.

Ideally, the exit site should be undisturbed for 7–10 days following insertion of the catheter. The patient may be discharged home during this period. If, during the first 10 days, the dressing becomes soiled, it should be redressed by a nurse. If it merely becomes dislodged, it should simply be replaced with a fresh sterile dressing. During this period, the catheter tubing must be immobilised by securely taping it to the patient's abdomen. Local unit policies will be in place and should be followed.

Before discharge from hospital, during this resting of the patient's catheter, clear instructions must be given as to the correct procedures for caring for the catheter at home. It may be appropriate to involve the community district nursing team if no specific community PD nurse is available. In this case, adequate training and support must be provided for the nursing team. Where possible, it is recommended that post-operative dressing changes be undertaken by experienced PD nursing staff (Crabtree et al. 2019).

Directly following insertion of the catheter, it may be flushed with 500–1500 ml of PD fluid to check patency. It may then be 'capped off' using a small locking cap on the

Table 8.1 Suggested Guidelines for Selecting a Peritoneal Dialysis Catheter Insertion Approach.

	Previous major surgery or peritonitis (Order of suggested technique)	No previous major surgery or peritonitis (Order of suggested technique)
Patient suitable for general, anaesthesia	• Advanced Laparoscopic • Open surgical dissection	• Advanced laparoscopic • Image-guided percutaneous • Open surgical dissection <i>or</i> Peritoneoscopic • Percutaneous without image-guidance
Patient only suitable for local anaesthesia/sedation	• Open surgical dissection	• Image-guided percutaneous • Open surgical dissection <i>or</i> Peritoneoscopic • Percutaneous without image-guidance

(Adapted from Crabtree et al. 2019)

catheter adapter (this adapter is available in titanium metal or plastic) and left covered until PD commences. Ideally, PD should not be started until healing of the exit site and tissue ingrowth into the catheter's Dacron cuffs have taken place, usually after 10 days. If dialysis is necessary before this time, automated PD would be the preferred method. This is because this treatment will help to minimise the risk of leakage of PD fluid by allowing the patient to be treated using small fill volumes of fluid in a supine position. It is worth noting that patient-healing mechanisms may be altered in those patients who are uraemic or who have diabetes mellitus.

LONG-TERM CARE OF THE EXIT SITE

As with any wound, care is aimed at keeping the site clear of exudate or debris that could encourage bacterial growth. A method of exit-site care that best fits in with the patient's lifestyle is most likely to encourage full participation in the treatment, and therefore reduce the risk of complications. A number of studies have been undertaken to attempt to ascertain which particular method of exit-site care is preferred. Various protocols do exist – for example, cleansing with soap and water or cleaning with povidone-iodine; however, there is to date no consensus on which method will reduce the incidence of infection (Twardowski and Nichols 2009).

Whichever solution is chosen, the following points should be considered:

- Harsh solutions should be avoided as they have the potential to cause skin damage, which may predispose to bacterial colonisation.
- Different agents may be preferred in different circumstances. In those who are immunosuppressed, the normal skin flora may represent an infection risk; in this case an antiseptic solution may be preferred.
- Whichever method is used, it is important to ensure that the exit site is carefully dried to avoid skin maceration, which could predispose the site to bacterial colonisation.

There is also some debate as to whether it is necessary to keep the catheter exit site covered. The use of no dressing and a simple exit-site care routine for a well-healed exit site would appeal to many; however, most centres do use some kind of cover.

CATHETER IMMOBILISATION

From the moment the catheter is inserted, it should always be securely anchored to the patient's skin to avoid torque movements at the exit site. This has been shown to reduce the risk of exit-site infection (Mushahar et al. 2016) and

can be achieved by using tape or a commercially available immobilisation device or tube holder.

SWIMMING AND BATHING

Swimming and bathing can be discussed with patients once the exit site is fully healed and ideally free from infection, with the following recommendations:

- A waterproof or occlusive dressing should be applied (there are specialist products available) and the exit site should be cleaned and new dressing applied immediately after immersion in water using normal technique.
- It is suggested that swimming or other water sports should take place in either sea water or swimming pools that are known to be well maintained (private or municipal), avoiding open water directly after storms to limit exposure to waterborne pathogens (Bennett et al. 2022).

INDICATIONS FOR CATHETER REMOVAL

A PD catheter is designed to be a permanent access device, and its removal should not be routine. However, catheters may have to be removed under the following conditions (Crabtree et al. 2019). See Box 8.1.

BOX 8.1

CONDITIONS FOR POSSIBLE CATHETER REMOVAL

- Peritonitis
- Flow dysfunction
- Pericatheter leak and hernia
- Kidney transplantation
- Improved kidney function
- Dialysis inadequacy
- Elective transfer to haemodialysis

ISPD guidelines (Crabtree et al. 2019) recommend the following catheter insertion outcomes be audited at least annually:

- Catheter patency at 12 months of >95 % for advanced laparoscopic placement and >80% for all other catheter insertion methods.

- Exit-site / tunnel infection within 30 days of catheter insertion: <5%
- Peritonitis within 30 days of catheter insertion: <5%
- Visceral injury (bowel, bladder, solid organ): <1%
- Significant hemorrhage requiring transfusion or surgical intervention: <1%
- Suggests that incidents of pericatheter leaks within 30 days of catheter insertion be recorded separately for early PD starts (<14 days) and late starts (≥ 14 days).

PERITONEAL DIALYSIS THERAPY OPTIONS

Dialysis should be prescribed according to each individual patient's clinical and lifestyle needs. The dose of PD can be increased or decreased by adjusting any one of the following parameters:

- dialysis fluid fill volume per exchange;
- number of dialysis fluid exchanges;
- length of dialysis fluid dwell time;
- osmotic strength or type of dialysis fluid.

PD prescriptions are now focused on the person doing PD and should be 'goal-directed'. This involves discussions between the individual and the care team (shared decision-making) to establish care goals for dialysis delivery (Brown et al. 2020). There are several goals:

- Allow the person doing PD to achieve his / her own life goals.
- Minimize symptoms and treatment burden.
- Promote the provision of high-quality dialysis care by the dialysis team.

Further assessments can help ensure delivery of high-quality PD care:

- *Patient reported outcome measures.* This measures how a person doing PD is experiencing life and his / her feeling of well-being, taking into account symptoms, impact of the dialysis regimen on the person's life, mental health, and social circumstances.
- *Fluid status.* This is a regular assessment of urine output and fluid removal, including blood pressure and clinical examination.
- *Nutrition status.* Evaluation of patient's appetite, clinical examination, body weight measurements and blood tests (including assessment and adjustment – as needed, of dietary intake of potassium, phosphate, sodium, protein, carbohydrate and fat).
- *Removal of toxins.* This can be estimated using a calculation called Kt/V_{urea} and/or creatinine clearance.

There are two general methods of performing PD: CAPD and APD.

CONTINUOUS AMBULATORY PERITONEAL DIALYSIS

CAPD (Figure 8.11) is carried out during the daytime, manually by patients themselves. Dialysis fluid is infused into the peritoneal cavity and left to dwell for 3–10 hours (if overnight). After this time the dialysate is drained from the cavity, fresh solution is infused, and the whole process starts again. Patients usually perform four exchanges of PD fluid each day, fitting them in as appropriately as possible with their normal lifestyle. For example, exchanges may be performed at breakfast, lunch, and supper time with the last exchange of the day being carried out at bedtime. Each exchange takes about 20–30 minutes to complete.

CAPD is most suited to those patients whose membranes transport solutes at an average rate as it provides the opportunity for longer dwell times. This long dwell period is best achieved during the nighttime whilst the patient sleeps. Those patients whose membranes transport solutes

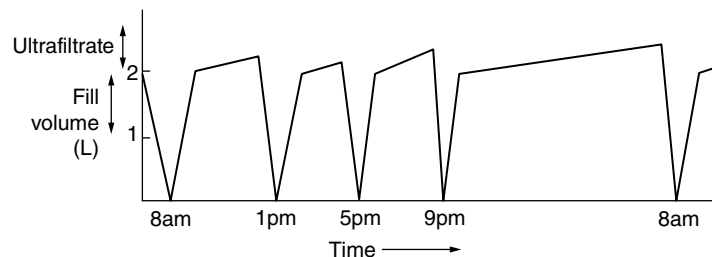


FIGURE 8.11 Continuous ambulatory peritoneal dialysis (CAPD).

quickly (fast peritoneal solute transfer rate (PSTR)), may need to use an icodextrin solution for the longest dwell overnight. This will avoid dialysate fluid absorption which could occur in these patients during long dwell periods.

AUTOMATED PERITONEAL DIALYSIS

APD is carried out by a machine, which performs the dialysis fluid exchanges at night whilst the patient sleeps. An APD machine automatically controls the fill volume, dwell time, and length of treatment the patient receives. The dose of dialysis can easily be increased during APD as it is easy and convenient to alter the parameters of the treatment. Dialysis fluid-fill volumes can be more safely increased due to the reduction in intra-abdominal pressure achieved whilst the patient is supine. This not only decreases the risk of problems associated with high intra-abdominal pressure such as leaks around the catheter exit site, abdominal hernias, and back pain, but it also increases the amount of dialysis the patient can achieve.

The length of the dwell time and the number of exchanges can effectively be altered without disruption to the patient's lifestyle. Performing frequent exchanges is essential for these patients to achieve adequate dialysis but this can be inconvenient if the patient is on CAPD. APD provides an effective and convenient alternative by enabling rapid exchanges of dialysis fluid whilst the patient sleeps. This increases the clearances of solutes whilst maintaining maximum UF. As with CAPD, the osmotic strength of the fluid can be altered according to each patient's need.

APD is particularly suitable for those patients needing to be free during the daytime. Patients who work or who are studying can benefit from this treatment, as the preparation time for the treatment is short and the dialysis takes place whilst they sleep, leaving them free during the day. APD is also suitable for those patients who rely on a carer to perform their dialysis, for example children, older people, or those with disabilities. The carer simply prepares the machine, connects the patient to the machine at

bedtime, and disconnects them the following morning. APD is therefore an effective therapy option for those patients who require more dialysis and/or freedom during the daytime. However, in order to achieve adequate dialysis, many patients will also need to perform an exchange in the early evening.

Some APD machines have the facility to store information regarding the patient's therapy on a data card that is fitted inside the machine or to a connectivity platform. This enables storage of the patient's individual prescription, enabling the prescription to be altered by a healthcare professional, without the need for the patient's intervention.

There are three types of APD:

1. continuous cycling peritoneal dialysis (CCPD);
2. tidal peritoneal dialysis (TPD);
3. optimised cycling peritoneal dialysis (OCPD).

CONTINUOUS CYCLING PERITONEAL DIALYSIS

The 'continuous' part of the acronym is derived from the fact that the patient has dialysis fluid in constant contact with the peritoneal membrane (Figure 8.12). There are typically between five and seven exchanges of fluid with relatively short dwell periods, so maximising the UF and clearance capabilities of those patients whose membrane transports solutes quickly. The treatment regime can be programmed to end with a 'fill', giving the patient a 'wet day' (the fluid would be left inside the peritoneal cavity during the day and drained when the patient next starts treatment on the machine at bedtime). Icodextrin solution, designed for long dwells, should preferably be used in these circumstances.

Rarely, the treatment ends following the 'drain', giving the patient a 'dry day'. This may help to prevent absorption of the PD fluid in 'high transporters'. It should be noted, though, that utilising a 'dry day' will result in severely reduced clearances and possibly underdialysis.

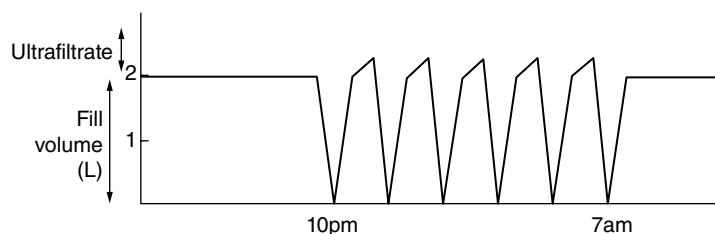


FIGURE 8.12 Continuous cycling peritoneal dialysis (CCPD).

TIDAL PERITONEAL DIALYSIS

Tidal PD is a form of APD where the dialysis fluid fill volume is not fully drained after each cycle (Figure 8.13). It is typically used for patients who experience pain at the end of each drain phase, particularly for new or acute patients getting used to the sensation of fluid in the peritoneal cavity. By leaving a small 'sump' volume of about 10% of the dialysis fill volume in the patient's peritoneal cavity at the end of each drain phase, pain is minimised. A full drain takes place at the end of the therapy during the final drain. It is important to remember to check the minimum drain volume parameters to avoid IIPV (increased intraperitoneal volumes) and associated risks.

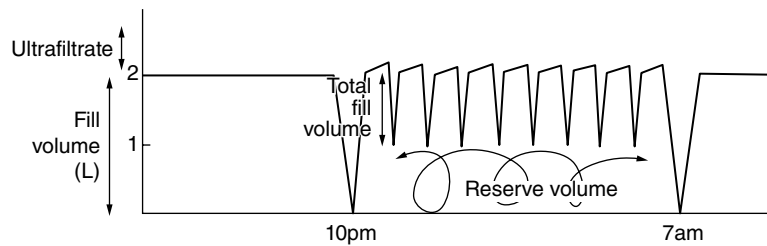


FIGURE 8.13 Tidal peritoneal dialysis (TPD).

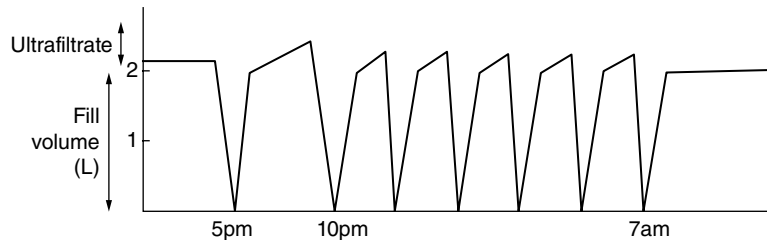


FIGURE 8.14 Optimised cycling peritoneal dialysis (OCPD).



FIGURE 8.15 One type of APD machine. *Source:* © sleep•safe harmony I Fresenius Medical Care Deutschland GmbH.

OPTIMISED CYCLING PERITONEAL DIALYSIS

This method of APD enables the delivery of more dialysis as the patient's RRF declines (Figure 8.14). During OCPD, the patient performs overnight CCPD or TPD as well as adding a daytime exchange of PD fluid. Some APD machines are designed so that the patient can perform both the night and day exchanges using the same disposable equipment and solution bags. The longer dwell of fluid during the daytime will optimise clearance opportunities and the shorter dwells of the nighttime dialysis will help to achieve UF goals.

Whichever method of PD is chosen for the patient at any particular time, it should provide a balance between clinical and lifestyle needs. Figure 8.15 is an example of one type of APD machine.

PATIENT SELECTION

The Renal Medicine Getting It Right First Time (GIRFT) Programme National Specialty Report recommends that home therapy is promoted and offered for all suitable patients and that a minimum prevalent rate of 20% is achieved in every kidney centre (Lipkin and McKane 2021).

An important consideration when developing a successful PD programme is good patient selection. Treating the most appropriate patients with PD will avoid the patient being subjected to increased risk of morbidity and mortality. In the early years of PD, selection was mainly based on the patient’s inability to have HD – for example, those patients with poor or no vascular access, poor biochemical control on HD with high predialysis serum levels of creatinine, those patients with poorly controlled hypertension, and those with excessive fluid gain between dialysis sessions. Positive selection criteria are now preferred as PD has proven to be a successful viable alternative to HD as a treatment for end-stage kidney disease.

Tables 8.2 and 8.3 indicate which patients are more suited to APD and those who are more suited to CAPD.

ASSISTED PERITONEAL DIALYSIS (ASPD)

The number of patients needing dialysis is increasing with the majority being treated with in-center hemodialysis, despite many advantages of PD for older people. If given a choice, older people would like to have PD, because it is a home-based therapy, but need some degree of assistance whilst performing the therapy. Challenges such as decreased strength to lift PD bags, decreased dexterity and vision, anxiety, and cognitive impairment may limit performance of self-care PD.

One solution is asPD, a modality performed at the patient’s home with the assistance of a healthcare technician, a community nurse or a family member, or a partner (Van Der Sluijs et al. 2021). Therefore, asPD increases access to dialysis at home, particularly for the increasing number of older and frail people (Brown et al. 2022). It is also suitable for others who have challenges to undertake PD themselves, such as those with learning disabilities or patients being cared for by young family carers,

PERITONEAL DIALYSIS FOR THOSE WITH DIABETES

Diabetic kidney disease is one of the main causes of end-stage kidney disease worldwide. Although death rates of patients with diabetes on HD and PD have decreased substantially, they remain higher than rates in non-

Table 8.2 Criteria for determining patient suitability for continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD).

Suited to CAPD	Suited to either CAPD or APD	Suited to APD
Patients whose membranes transport solutes slowly or at an average speed.	Those who prefer home-based therapy.	Patients who seek daytime freedom to attend work or school.
	Patients with complicating cardiovascular disease.	Patients at risk of complications associated with raised intra-abdominal pressure.
	Children with small body size.	Patients who require a carer to perform their dialysis.
	Patients with poor vascular access.	Patients with chronic backache.
	Patients with diabetes mellitus.	Patients who require enhanced dialysis, i.e. those without residual renal function (RRF).
	Patients with severe hypertension.	
	Patients with anaemia.	
	Patients who wish to travel.	

Table 8.3 Conditions that could make continuous ambulatory peritoneal dialysis (CAPD) or automated peritoneal dialysis (APD) unsuitable for a patient.

Unsuitable for CAPD	Unsuitable for either CAPD or APD
Patients with chronic back pain.	Patients with chronic obstructive lung disease.
Patients at risk of complications associated with raised intra-abdominal pressure.	Patients with diverticular disease.
	Patients who are unable to care for themselves and do not have the assistance of a full-time carer.

diabetics on both modalities. PD offers equal survival compared with HD for younger patients with diabetes during early years of dialysis. Mehrotra et al. (2011) describes the benefit of preserving vascular access in patients who often have poor vasculature.

BLOOD GLUCOSE CONTROL

There is an increasing number of people living with diabetes and PD worldwide. However, there is a lack of guidelines and clinical recommendations for managing glucose control in people with diabetes on PD (Wijewickrama et al. 2023). A patient using only glucose-based solutions will absorb between 100 and 150 g of glucose per day from the dialysis fluid. This can lead to problems for those with diabetes. Glucose-free solutions (Icodextrin and amino-acid solutions) provide an excellent solution for people with diabetes, as the use of these fluids significantly reduces the amount of glucose absorbed by the patient.

In a study by Li et al. (2013) where both icodextrin and amino acid PD dialysis fluids were compared with usual glucose solutions, there was a 0.5% reduction in glycated haemoglobin in the icodextrin/amino acid group. However, as there was an increase in adverse events and deaths in this group, including events related to extracellular fluid expansion, it is critical that this approach with use of low-glucose solutions is accompanied by careful monitoring of hydration and glucose levels (Woodrow et al. 2017).

Capillary blood glucose monitoring remains the most used method of assessing daily glycemic variability in diabetes. However, it should be chosen with caution because certain types of glucometers give rise to false readings. Presence of rapidly evolving technologies such as Intermittent scanned (flash) and real-time CGM systems are increasingly used. These measure interstitial glucose concentrations at regular intervals allowing the assessment of glycemic variability and detection of asymptomatic hypoglycemia and hyperglycemia, providing extremely useful low alerts when detecting asymptomatic hypoglycemia. However, their utility in care of patients having PD is still being defined.

Glycated HbA1c, despite the limitations, is currently the preferred marker for long-term glycemic control assessment in people with diabetes receiving PD. Other markers such as glycated albumin or fructosamine may be less reliable than HbA1c in PD. The use of glucose dehydrogenase and coenzyme pyrroloquinoline-quinone-based glucometers or strips are to be avoided because these can give falsely elevated blood glucose readings in people undergoing PD with icodextrin and can result in the risk of excessive treatment and iatrogenic hypoglycemia. (Wijewickrama et al. 2023)

Blood sugar control for patients with diabetes on PD should be subcutaneous insulin or oral agents, or dietary control. Any combination of these methods can be used.

ADMINISTRATION OF INSULIN

Intraperitoneally administered insulin has previously been advocated to mitigate the additional glucose load associated with PD (Quellhorst 2002). However, multiple studies have reported adverse effects, including abnormal lipid profile, hepatic subcapsular steatosis, and increased risk of peritonitis. Only subcutaneous insulin administration is recommended. (Wijewickrama et al. 2023).

Ikizler et al. (2020) states guidelines recommended for PD patients a minimum dietary protein intake of 1.0 to 1.2g/kg/d, matched to the ideal body weight to account for the protein losses during dialysis and for maintenance of a good nutritional status. Approach should be individualized considering comorbidities, as well as diabetes treatment such as insulin and patient preferences.

Wijewickrama et al. (2023) recommends an individualized approach to the management of diabetes with consideration of risks of hypoglycemia, comorbidities, type of PD and glucose content of dialysate is required. Considering that PD can have a significant impact on glycemic control, for monitoring of glucose and treatment choices, a collaborative management approach between different health care professionals is also required. Individualized insulin titrations and regimens and for all diabetic PD patients to receive education on the risk of hypoglycemia, advice on mitigating risks and guidance on self-management.

SOLUTION FORMULATION

PD solution is presented in sterile plastic bags with a protective over-pouch in volumes of 500-, 750-, 1000-, 1500-, 2000-, and 2500-ml. Bags of 5000 ml are available for use with APD machines. The electrolyte concentration of dialysis fluid is similar to that of normal serum, with lactate acting as a bicarbonate-generating agent to combat metabolic acidosis, which is common amongst patients. Electrolyte composition of the dialysis fluid has been changed several times over the years. A major challenge when treating patients with kidney disease has been effective phosphate control. Consequently, dialysis fluid does not contain any phosphate, and patients are given oral phosphate-binding agents to help eliminate dietary phosphate intake from the body.

GLUCOSE-BASED SOLUTIONS

Up until the early 1990s, the most prescribed and the most widely available osmotic agent used in PD was glucose. Glucose-based dialysis fluid comes in three strengths

(1.36, 2.27, and 3.86% monohydrate glucose). The strong (hypertonic) solutions provide greater osmotic strength. Patients should use 1.36% glucose most often whilst their weight is within 0.5 kg of their 'dry' or 'target' weight. Hypertonic solutions should be used when the patient has fluid overload. Most patients ultrafiltrate an extra 200–600 ml by using a 2000 ml medium (2.27%) glucose solution bag and an extra 400–1000 ml by using a 2000 ml strong (3.86%) glucose solution bag. Patients should be taught to record their body weight daily and choose the appropriate solution strengths for that day.

UF by hypertonic solutions is maintained for approximately 8 hours in most patients. After this time some reabsorption of fluid may occur. In those patients whose membranes transport solutes quickly (*fast PSTR*), reabsorption may occur sooner than 8 hours, giving rise to the need to use an icodextrin fluid exchange for the longer dwell times (i.e. the overnight dwell in CAPD or the daytime dwell in APD).

ICODEXTRIN PERITONEAL DIALYSIS SOLUTION

There are problems associated with the use of glucose as an osmotic agent, such as hyperglycaemia and hyperlipidaemia. Patients who have poor UF provide the greatest challenge in this area. Worsening fluid balance results in reduced technique and patient survival. Icodextrin solution is known to improve UF in the long dwell during PD (Silver et al. 2014).

Icodextrin 7.5% is a formulation of a large molecular-weight glucose polymer, which is a more biocompatible solution as it is approximately iso-osmolar with serum. The use of this larger molecule means that less glucose is available for absorption through the peritoneal membrane. Its long-acting UF performance (up to 12 hours) is combined with low carbohydrate absorption. Icodextrin reduces the exposure of the peritoneal membrane to glucose for more than 50% of the dialysis time if used for the long dwell and improves fluid balance and BP control compared with 2.27% glucose (Lin et al. 2009).

Paniagua et al. (2002) demonstrated that patients using icodextrin had significantly reduced glucose exposure and this was, in turn, associated with stabilisation of weight in patients with diabetes.

UK Renal Association standards (Woodrow et al. 2017) recommend that specialised solutions such as glucose polymers (icodextrin) are preferable for patients with fast PSTR.

BICARBONATE/LACTATE-BASED PERITONEAL DIALYSIS SOLUTIONS

Bicarbonate/lactate solutions were developed following extensive research to identify the most suitable alternative

formulation to the traditional lactate buffered solutions. The commercially available solution comes in a double-chambered bag because some of the compounds of the bicarbonate/lactate solution are not stable during the steam sterilisation process. Glucose needs to be in acidic conditions (low pH) to prevent caramelisation. Since the bicarbonate/lactate solution is neutral, the glucose must be separated from the other compounds. The glucose sits in the upper, smaller chamber, together with calcium and magnesium salts, under acidic conditions. The bicarbonate, lactate, and sodium salt sit in the lower, larger chamber. The two solutions are mixed just before infusion (usually whilst the patient is draining the used fluid during CAPD or during the setup of the APD machine).

There is growing evidence that regular use of hypertonic glucose dialysis fluid (3.86%), and where possible glucose 2.27%, is to be avoided as far as possible. It is associated with acceleration in the detrimental changes in membrane function that occur with time on treatment, as well as several undesirable systemic effects including weight gain, poor diabetic control, and adverse haemodynamic effects (Woodrow et al. 2017). Substituting icodextrin for glucose solutions during the long exchange will result in equivalent ultrafiltration whilst avoiding the systemic effects of the glucose load.

Physiological pH and bicarbonate concentration

Bicarbonate is the natural buffer of the body. As a result of the metabolism of ingested foods, our body produces hydrogen ions (protons). This acid must be excreted or neutralised to maintain the body's acid–base balance. The kidneys play a key role in maintaining acid–base balance. Not only do they excrete hydrogen ions but they also regenerate bicarbonate. In people with kidney disease this function is impaired or lost. It is important to replace the lost bicarbonate to maintain the acid–base balance and prevent the occurrence of acidosis. Using bicarbonate in the PD solution is the most natural way of restoring the bicarbonate level. Alternative buffers, like lactate, need some conversion (metabolism) before they result in bicarbonate.

The biocompatibility of a PD solution has been defined as the ability of a solution formulation to permit adequate long-term dialysis without a clinically significant undesirable host response (*Consensus Conference on Biocompatibility* 1994). These objectives will best be met by solutions whose composition is identical to the composition of extracellular fluid in the body, in particular to the composition of blood.

AMINO ACID BASED PERITONEAL DIALYSIS SOLUTION

Intraperitoneal amino acid (IPAA) solution contains 15 amino acids. Eight are essential amino acids, two are considered essential to patients with kidney disease, and five are nonessential. The osmotic agent glucose is replaced by 1.1% amino acids, which have the comparative UF capability of 1.36% glucose solution. After a 4- to 6-hour dwell, 65–95% of the amino acids are absorbed, the equivalent to about 18 g (from a 2000 ml bag containing 22 g of amino acids), or $0.3 \text{ g kg}^{-1}\text{day}^{-1}$ in a 70 kg patient. This is approximately 25% of the daily protein requirement for a patient on PD.

IPAA is administered in the same way as other PD solutions. It is prescribed for one exchange per day, replacing one of the usual glucose dialysis solution bags or mixed with overnight glucose solutions during APD. If given during the day, it should be given either at a main meal or with a high-calorie snack, as this will ensure that the amino acids are used in the anabolic process to generate protein rather than being expended as an energy source. The use of 1.1% amino acid PD solution, when used instead of one glucose exchange, decreases both peritoneal membrane glucose exposure and systemic glucose absorption.

Patients will benefit from using a combination of all the available solution formulations, including amino acid, polyglucose, bicarbonate/lactate, and glucose. UK Kidney Association Guidelines (Woodrow et al. 2017) offer advice on using different PD solutions, including the suggestion that biocompatible solutions (normal pH and/or low concentrations of glucose degradation products) be considered for preservation of residual kidney function. Currently there is insufficient evidence to recommend that all patients should be treated with biocompatible solutions, especially as this may have a significant cost implication.

ASSESSING PERITONEAL DIALYSIS ADEQUACY

There are a number of ways in which dialysis adequacy can be measured and all parameters must be taken into consideration:

- creatinine clearance – a solute-removal test based on body surface area;
- Kt/V – a urea index relating urea clearance to the volume of urea distributed in the body;
- protein nutrition;
- general well-being.

See Chapter 12 for further general information on dialysis adequacy and nutrition.

The prescription index Kt/V was developed by Gotch et al. (1983) and Gotch and Sargent (1985) in the National Co-operative Dialysis Study of patients on HD. Kt/V is an index of urea removal, which is patient-specific as it looks at urea removal achieved over time ($K \propto t$) and measurement of urea in the body water (V) for each patient. Therefore: K = clearance; t = time; V = volume of body water in which urea is distributed.

PRESCRIBING IN PD

ISPD guidelines (Brown et al. 2020) recommend that PD prescription should be ‘goal-directed’. The guideline recommendations are:

- *PD prescription should involve shared decision-making.* This involves discussions between the person doing PD and the care team aiming to establish realistic care goals that (1) maintain high quality of life enabling them to meet their life goals, (2) minimize symptoms and treatment burden, while (3) ensuring high-quality care is provided.
- *PD prescription should consider the local country resources, the wishes, and lifestyle considerations of people needing treatment.* That includes those of their families / caregivers, especially if providing assistance in their care.
- *Assessments to help ensure high-quality PD care is delivered.* These include:
 1. *Patient-reported outcome measures.* These measure how a person doing PD is experiencing life and his / her feeling of well-being. It should consider the person's symptoms and impact of the dialysis regimen on the person's life, mental health, and social circumstances.
 2. *Fluid status.* Urine output and fluid removed by dialysis both contribute to maintaining good fluid status. Regular assessment of fluid status, including blood pressure and clinical examination, should be part of routine care.
 3. *Nutrition status.* This should be assessed regularly through evaluation of patient's appetite, clinical examination, body weight measurements and blood tests (potassium, bicarbonate, phosphate, albumin). Dietary intake of potassium, phosphate, sodium, protein, carbohydrate, and fat may need to be assessed and adjusted as well.

4. *Removal of toxins.* Estimated using Kt/V_{urea} and / or creatinine clearance. Both measures the amount of dialysis delivered – although there is no high-quality evidence regarding the need or benefit associated with the achievement of a specific target value for these measures.
5. *Kidney function and urine volume.* The amount of kidney function that continues to remove waste products and the remaining urine volume should be known for all individuals doing PD. Management should focus in preserving this as long as possible.
6. *Quality of life.* For some people who require dialysis and who are old, frail, or have a poor prognosis, there may be a quality-of-life benefit from a reduced dialysis prescription to minimize the burden of treatment.

Adequacy

UK Renal Association (now UK Kidney Association) guidelines (Woodrow et al. 2017) recommend combined urinary and peritoneal small solute clearances of $Kt/V > 1.7 \text{ week}^{-1}$ or a creatinine clearance of $>50 \text{ l week}^{-1} 1.73 \text{ m}^{-2}$ to be considered as minimum treatment doses and should be measured every 6 months in patients who are stable but more frequently if a patient's condition determines. The guidelines recommend that this is a minimum treatment dose and should be increased in patients experiencing symptoms, again reinforcing the importance of the patient's quality of life.

Updated ISPD recommendations (Boudville and de Moraes 2020) state that:

- Residual renal function (RRF) has consistently demonstrated to be associated with mortality in people doing PD therefore should be maintained.
- Total weekly clearances (i.e. the mathematical sum of residual clearance with peritoneal clearance) have never been shown to be based on evidence though the convenience of this measure is recognized.
- There is no evidence that increasing weekly $Kt/V > 1.7 - 1.8$ provides survival advantage.
- There is evidence that weekly $Kt/V < 1.7$ is associated with increased morbidity.
- In anuric people doing PD, a weekly Kt/V of at least 1.7 is recommended to prolong survival.
- Ultrafiltration (UF) is associated with overall and technique survival, but no numerical target can be recommended.

- Icodextrin is recommended to improve UF independent of the dialysate / plasma (D/P) creatinine. There is no apparent risk of adverse side effects or impact on RRF.

There are several computer programmes available that will calculate the patient's Kt/V , creatinine clearance, and nutritional status. Some of these programs will also model the patient's treatment, allowing the nurse or physician to look at a wide range of PD therapy options for the optimal regime that meets the adequacy needs of each individual patient. This enables the clinician to eliminate the trial-and-error process of prescribing PD, takes away the need to perform manual calculations, and provides the kidney unit with a database of their patients' quality of dialysis.

If patients are no longer achieving these adequacies the prescription can be increased, considering the patient's lifestyle and how these changes can be accommodated within reason. As this potentially becomes more difficult with the membrane beginning to deteriorate with the loss of RRF, the possible need for the change to HD should be explored to allow the patient time to rationalise this choice. The patient's reasons for choosing PD should be remembered and the implications of changing therapies on their lifestyle should be balanced with the patient's clinical condition to allow for a collaborative decision to be made.

LONGITUDINAL CHANGES TO THE PERITONEAL MEMBRANE

The peritoneal membrane has proven to be remarkably resilient and there are a number of early studies that have shown it to be stable over time (Selgas et al. 1998; Davies et al. 2001; Kendrick and Teitelbaum 2010).

Long-term changes, such as thickening of the peritoneal membrane, can cause a loss of UF (Davies et al. 2005). This may be associated with exposure of the membrane to the harmful effects of glucose-based solutions (such as glucose degradation products), peritonitis, or uraemic toxicity. In fact, a marked thickening of the membrane is only seen in patients who experience more than two episodes of peritonitis, but thickening was shown in patients who used hypertonic glucose solutions (Kendrick and Teitelbaum 2010).

It has been demonstrated that by avoiding the use of hypertonic glucose solutions, functional changes in the peritoneal membrane can be avoided for at least five years (Davies et al. 2001), but the catheter itself can cause membrane changes (Kendrick and Teitelbaum 2010).

It is worth noting also that thickening of the peritoneal membrane has been seen in patients with uraemia before the onset of dialysis (Plum et al. 2001) suggesting

that uraemia itself may cause peritoneal membrane changes.

ENCAPSULATING PERITONEAL SCLEROSIS (EPS)

Encapsulating peritoneal sclerosis (EPS) is a rare, but serious complication of long-term PD. It involves formation of an inflammatory, and later fibrotic, 'cocoon' surrounding the gastrointestinal tract which results in features of abdominal inflammation and intestinal obstruction (Johnson et al. 2010).

A combination of bowel obstruction and features of encapsulation due to peritoneal fibrosis with symptoms of anorexia, vomiting, and weight loss are common. The step-wise process of symptom progression is important. Computed tomographic (CT) scanning is recommended that will have shown features of peritoneal calcification, bowel thickening, bowel tethering, and bowel dilatation. These findings do not suffice EPS diagnosis with the absence of the symptoms above and many long-term PD patients will have thickening of the peritoneal membrane without EPS. (Brown et al. 2017).

One study of 111 patients in the United Kingdom with EPS (one of the largest cohorts of patients with EPS in the literature) found that long-term survival occurred in over 50%, regardless of the various treatment strategies undertaken by various centres (Balasubramaniam et al. 2009).

There is no single strategy to reduce EPS risk that is proven; however, some evidence had shown to support minimizing dialysate glucose exposure (ensure that fluid volume status is not compromised); prevent acute PD-related peritonitis; use neutral-pH, low-glucose degradation product dialysis solutions (Brown et al. 2017).

There is no evidence to withhold PD as a treatment option, and there is insufficient evidence to support a single rule about optimal length of time on PD – due to fear of developing or avoiding the risk of EPS. The following should be discussed, and any decision arrived at by shared decision-making:

1. age and prognosis of patient;
2. length of time on PD;
3. quality of PD (dialysis adequacy, ultrafiltration, peritonitis frequency);
4. access to and suitability for transplantation;
5. potential risk of HD in the particular patient (hemodynamic stability, vascular access); and
6. quality of life of the patient (Brown et al. 2017).

FLUID MANAGEMENT IN PERITONEAL DIALYSIS

During PD, hyperosmolar dialysis solution removes fluid by the process of osmosis. Water transport across the peritoneal membrane depends upon the concentration of glucose in the dialysis solution and the size of the pores in the peritoneal membrane. At the same time as fluid is being removed from the blood through osmosis, fluid is continually being reabsorbed through the lymphatic system. In addition, the osmotic gradient is continually reducing due to dilution of the PD solution (by the ultrafiltrate) and absorption of glucose into the blood. Therefore, there comes a point in time during the PD fluid exchange when fluid removal no longer takes place and fluid is reabsorbed back into the patient. This will occur before solute equilibrium.

Fluid removal and fluid balance can be enhanced in patients on PD by increasing the glucose concentration of the dialysate, increasing the volume of fluid used (although a substantial increase in intra-abdominal pressure may reduce UF due to the increased pressure), optimising the dwell time/using APD, reducing sodium intake, and by using icodextrin solutions (Woodrow et al. 2017).

PROBLEM SOLVING IN PERITONEAL DIALYSIS

PROTEIN LOSS

Protein is lost through the peritoneal membrane at a rate of 6–12 g day⁻¹ even in patients who are stable. To compensate for this loss, patients on PD need to eat between 1.0 and 1.2 g kg⁻¹ of body weight/day of dietary protein. This loss is increased during peritonitis when a patient can lose up to 20 g day⁻¹. See Chapter 12 for further details.

RAISED INTRA-ABDOMINAL PRESSURE PROBLEMS

Raised intra-abdominal pressure is caused by the pressure of high volumes of fluid in the peritoneal cavity. This pressure is further increased when the patient carries out strenuous exercise or suffers excessive coughing. Continuously raised intra-abdominal pressure can increase the risk of abdominal hernias such as inguinal, incisional, diaphragmatic, or umbilical, and of dialysate leakage around the catheter exit site.

Oedema of the labia in females and the scrotum and penis in males is a distressing complication caused by dialysate leakage through soft tissues. It is usually easily

rectified by stopping PD for a short period (usually up to 1 week). Hernias and persistent leaks require surgical repair, while stopping PD for a time to allow the site to heal. If HD is not an alternative form of treatment for the patient during this temporary interruption to treatment, PD may be continued so long as the patient is lying down, therefore decreasing the intra-abdominal pressure (i.e. by using some form of APD).

In the event of dialysate leakage at the exit site, PD must be ceased immediately because the presence of a glucose-rich solution at a wound site gives rise to a markedly increased risk of infection. Leakage can be identified by using urine test sticks or blood glucose reagent strips at the exit site. The normal healing time for dialysate leakage is a week, but this may be increased in diabetes, severely uraemic, or malnourished patients.

Patients with previous vertebral disease may experience back pain due to the raised intra-abdominal pressure incurred in an upright position. In this situation APD may be the preferred therapy.

DRAINAGE PROBLEMS

These usually have a minor cause which, with proper patient training and education, can be rectified by the patients themselves at home. Reasons for poor inflow or outflow of dialysis fluid and their treatment are outlined in the next sections.

KINKS IN THE TUBING

The most common cause of poor drainage or inflow of PD fluid is tubing kinks or closed clamps. Patients should be taught to check the tubing for kinks and closed clamps as a first line of action in the event of poor in- or outflow of dialysis fluid. Catheter kinks sometimes occur due to malpositioning during surgical insertion. This will become apparent shortly after insertion, if not during the insertion procedure, and can be confirmed by X-ray (the PD catheter has a radiopaque stripe along its length). This problem is usually rectified by surgical intervention; however, it can occasionally be improved if the patient has a bowel motion.

CONSTIPATION

Constipation should be avoided in patients on PD, not only because it causes problems with dialysate outflow but also because diverticulosis of the colon increases the risk of peritonitis. Constipation prevention is achieved by

encouraging the patient to take a diet high in fibre along with a mild laxative if appropriate. Regular exercise is also recommended. If constipation does occur, treatment can be with laxatives or glycerine suppositories. The use of phosphate-containing enemas should be avoided due to the absorption of phosphate through the bowel during their administration.

FIBRIN FORMATION

Fibrin strands or plugs (a protein formed from fibrinogen in blood plasma in the process of clotting) in dialysate effluent are a common cause of poor drainage. The blockage, usually in the catheter or tubing, can normally be removed by 'milking' the tubing. Heparin may be added to the dialysis fluid (200–500 units l⁻¹) as a prophylactic measure, as it prevents the formation of fibrin.

If 'milking' the tubing does not remove the obstruction a fibrolytic agent can be used. Both streptokinase (250 000 i.u.) and urokinase (5000 i.u.) in 2–3 ml sodium chloride 0.9% for IV (intravenous) injection are available and should be infused into the catheter under aseptic conditions; the catheter should then be clamped, and the drug left to infuse for 2 hours. The catheter can then be checked for patency.

MALPOSITIONED CATHETER

If catheter obstruction is not relieved by any of the above techniques, the problem may be due to obstruction caused by omentum attached to the catheter tip. The omental attachment usually causes the catheter to migrate out of the pelvic cavity. In such cases it often proves difficult to resolve this problem without surgery.

It is possible to remove omentum from the catheter whilst leaving it in place during surgical procedure. It is common for the surgeon to perform a local omentectomy at the same time to prevent further obstructions by omentum. If it proves impossible to rectify the obstruction or position of the catheter by surgical methods, the final option is to remove the catheter completely and replace it with a new one.

SHOULDER PAIN

Occasionally, patients complain of shoulder pain following the infusion of fresh dialysis solution. This is thought to be a referred pain caused by intra-abdominal pressure or air under the diaphragm. Although it usually resolves within 10–20 minutes from onset, the patient may find relief by taking a mild analgesia such as paracetamol 1 g.

BLOODSTAINED EFFLUENT

This is a comparatively rare complication occurring most commonly in menstruating females. It may be due to endometriosis or retrograde bleeding through the fallopian tubes. The bleeding is usually mild and self-rectifies within a day or two without specific intervention.

More severe IP bleeding, causing darkly bloodstained fluid, can be caused by haemorrhage. This could be due to the patient straining whilst lifting a heavy object or suffering trauma to the abdomen and should be investigated.

INFECTIOUS COMPLICATIONS OF PERITONEAL DIALYSIS

Peritonitis is a common clinical problem that occurs in patients undergoing PD and can contribute to the failure of PD and hospitalisation. Severe and prolonged peritonitis can lead to peritoneal membrane failure (Kam-Tao Li et al. 2022).

Current ISPD recommendations on peritonitis (Kam-Tao Li et al. 2022) focus on five broad areas:

1. definitions and measurement of peritonitis;
2. prevention of peritonitis;
3. treatment of peritonitis: initial and subsequent;
4. monitoring response to peritonitis treatment including indications for catheter removal;
5. return to PD after cessation of PD due to peritonitis-related catheter removal.

CAUSES OF PERITONITIS

Most episodes of peritonitis are caused by organisms that are normal skin and nasal flora, for example *S. epidermidis* and *S. aureus*. Occasionally, water-borne organisms such as *Pseudomonas* may also cause this infection. There are five main routes of infection causing peritonitis, each one giving rise to common organisms.

INTRALUMINAL

Intraluminal contamination (at the solution bag and transfer set connection site) occurs most frequently when poor techniques have been used to make the connection. Good patient training and education regarding bag exchange procedure techniques and handwashing are essential. The incidence of this cause of infection has reduced in recent years due to the use of disconnect systems.

PERILUMINAL

Periluminal infection is introduced via the catheter tunnel from the exit site. Bacteria present on the skin surface can enter the peritoneal cavity via the catheter tunnel. This infection can occur if there is infection present at the exit site or in the subcutaneous tunnel which has migrated into the peritoneal cavity. The most common organisms seen when periluminal contamination has occurred are *S. epidermidis*, *S. aureus*, *Pseudomonas*, *Proteus*, and yeast. *S. aureus* nasal carriage is known to cause an increased risk of *S. aureus* exit-site infections, tunnel infections, peritonitis, and catheter loss. Prophylaxis with intranasal mupirocin exit-site mupirocin or oral rifampin has been shown to be effective in reducing *S. aureus* exit-site infections. The use of mupirocin ointment at the exit site, however, should be avoided in patients with polyurethane catheters (Cruz catheters) as structural damage to the catheter has been reported. All patients at an increased risk for *S. aureus* infections, including *S. aureus* carriers, those with diabetes, and immunocompromised patients, should be provided with prophylaxis. A practical approach is to prescribe exit-site mupirocin for all at-risk patients and so routine nasal swab tests are therefore not necessarily required in these patients.

TRANSMURAL

Transmural infection occurs through the gut wall. There is an association between both severe constipation and enteritis and peritonitis due to enteric organisms (Piraino et al. 2011). The most common organism seen as a transmural cause of peritonitis is *Escherichia coli*, although multiple contamination with anaerobes and fungi may also be isolated.

Also, peritonitis commonly follows endoscopic gastrointestinal and invasive or instrumental gynaecological procedures (e.g. gastroscopy, colonoscopy, hysteroscopy) in PD patients. It is therefore recommended to have antibiotic prophylaxis prior to colonoscopy and invasive gynaecological procedure; as well as the drainage of PD fluid to keep the abdomen empty before endoscopic gastrointestinal and invasive or instrumental gynaecological procedures (Kam-Tao Li et al. 2022).

HAEMATOGENOUS

An infection via the bloodstream is a rare cause of peritonitis and it may be peritonitis itself, which causes septicaemia. The most common organisms associated with this cause of peritonitis are *Streptococcus* and *Mycobacterium*.

VAGINAL

Peritonitis ascending through the vagina is thought to be from bacteria entering the peritoneum via the fallopian tubes. The most common causative organisms seen here are *Candida* and *Pseudomonas*.

PREVENTION OF PD-RELATED PERITONITIS

PD-related peritonitis is reported from the time the risk starts from the day of PD commencement (i.e. first day of PD training or PD treatment in hospital or at home with the intention of continuing PD long-term, whichever occurs first) and continues while a patient remains on PD regardless of the setting (home, hospital, residential aged care facility, etc.) or who is performing the PD exchanges. Every PD programme should monitor, at least on a yearly basis, the incidence and outcomes of peritonitis and should monitor this as part of a continuous quality improvement (CQI) programme.

The peritonitis rate should be measured as number of peritonitis episodes divided by number of patient years at risk (i.e. number of years on PD starting from the time of PD commencement), reported as episodes per patient years. The target is <0.4 episodes per patient-year. PD commencement is defined as the first day on which the first PD exchange was performed with the intention of continuing ongoing PD treatment (i.e. the first day of PD training or PD treatment in a hospital or at home with the intention of continuing PD long-term, whichever occurs first) (Kam-Tao Li et al. 2022).

The Advisory Committee for European Best Practice Guidelines (Kam-Tao Li et al. 2017) recommends the use of an assist device for all spiking procedures. The use of double-bag systems is preferred because they are more efficient in preventing peritonitis due to the flush-before-fill procedure.

The prevention of catheter exit-site infections is the primary goal of exit-site care. Once the catheter is placed, and until healing is completed, the dressing should be changed by a dialysis nurse using aseptic technique. The exit site should be kept dry until well healed, which means that showers or baths should not be taken for this period, which can take up to 2 weeks. Once the exit site is well healed, the patient should be taught how to do routine exit-site care. Antibacterial soap and water are recommended by many centres. Use of an antiseptic to clean the exit site is preferred in some programmes (Kam-Tao Li et al. 2017). Proper PD catheter immobilization and avoidance of mechanical stress on the exit site

may be useful to lower exit-site infection rate. Prompt treatment of exit-site or catheter tunnel infection is mandatory to reduce subsequent peritonitis risk (Kam-Tao Li et al. 2022).

In general, patients must be taught aseptic technique, with emphasis on proper handwashing techniques. If the water the patient uses is thought to have a high bacterial count, then use of an alcohol hand rub should be encouraged although this is used routinely in many centres. The hands must be completely dried using a clean towel after washing, before starting the exchange. The place where dialysis exchanges are carried out must be clean and free from animal hair, dust, and fans.

All patients can be taught what contamination is and what to do in the event of contamination. When patients report contamination during an exchange procedure, the need for treatment is driven by distinguishing “dry contamination” (contamination outside a closed PD system, such as disconnection distal to a closed clamp from “wet contamination” (referring to contamination with an open system, when either dialysis fluid is infused after contamination or if the catheter administration set has been left open for an extended period). Examples of wet contamination include leaks from dialysate bags, leaks or breaks in tubing proximal to the tubing clamp, and breach of aseptic technique or touch contamination of the connection during a PD exchange. Prophylactic antibiotics is only recommended after wet contamination. If unclear whether the tubing clamp was closed or open during contamination, wet contamination should be considered, for benefit of doubt. Wet contamination should also be monitored closely for an extended period (Kam-Tao Li et al. 2022).

The PD nurses are central to a successful PD programme that has low infection rates. Unfortunately, there are few if any studies on nurse-to-patient ratios that lead to the best outcomes. Overburdening the nurse with excessive numbers of patients will result in shortened training times and difficulty in retraining as needed. The Advisory Committee (Kam-Tao Li et al. 2017) recommends home visits. These may be very useful in detecting problems with exchange techniques, but only can be carried out if the nurses have sufficient time to do such visits.

DIAGNOSIS OF PERITONITIS

Early diagnosis allowing prompt treatment of peritonitis is essential in minimising damage to the peritoneal membrane. Peritonitis is diagnosed when at least two of the following are present (Kam-Tao Li et al. 2022):

- clinical features consistent with peritonitis, that is, abdominal pain and/or cloudy dialysis effluent;
- dialysis effluent white cell count $> 100/\text{ml}$ or $> 0.1 \times 10^9/\text{l}$ (after a dwell time of at least 2 h), with $> 50\%$ polymorphonuclear leukocytes (PMN);

positive dialysis effluent culture.

The process of diagnosis of peritonitis is summarised in Figure 8.16. It is recommended that patients presenting with cloudy effluent are presumed to have peritonitis and treated as such until the diagnosis can be confirmed or excluded.

OBTAINING A PD EFFLUENT SPECIMEN

Continuous ambulatory peritoneal dialysis

After disconnecting the drainage bag containing the effluent from the patient's transfer set, the bag should be inverted several times to mix the contents. Using strict

aseptic technique, a sample is taken by sterile needle and syringe from the sample port on the bag.

Automated peritoneal dialysis

A sample may either be taken from the daytime dwell, if the patient utilises a 'wet day' (i.e. dialysate in the peritoneum during the day), by attaching a drainage set and bag to the patient's extension set. The sample is then taken in the same way as for CAPD. Alternatively, if the patient is usually 'dry' during the day (i.e. no dialysate in the peritoneum during the day), there are a number of options. Some APD machines have a sample bag that can be attached to the drainage tubing. Alternatively, the patient may be taught how to take a sample from the drainage solution containers. If this is not possible, the patient may be asked to detach the drainage solution container from the machine following treatment and take this into the unit.

There are many different protocols for the treatment of PD peritonitis. An ad hoc advisory committee has reviewed experiences reported in the literature and devised

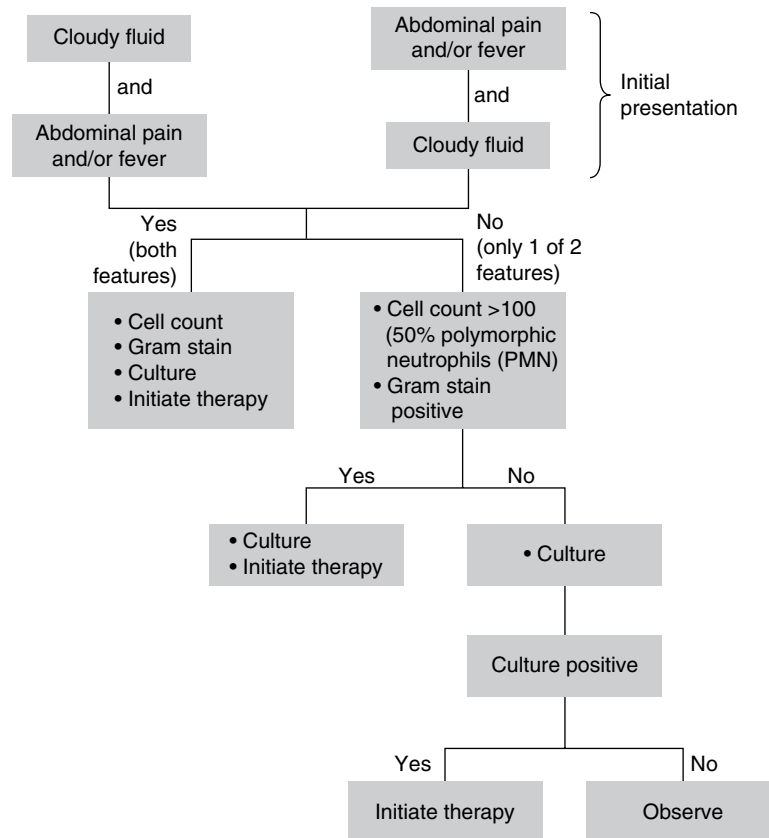


FIGURE 8.16 Initial clinical and laboratory assessment of a patient for peritonitis.

recommendations based upon these assessments. These recommendations were published in *Peritoneal Dialysis International*, most recently updated in 2022 (Kam-Tao Li et al. 2022). Antibiotics have been administered IP, IV, or orally, and a number of different dosing regimens have been utilised. The ISPD recommendations (Kam-Tao Li et al. 2022) include advice on treating peritonitis due to the most common organisms such as coagulase-negative *Staphylococcus*, *Streptococcus*, *Enterococcus*, *Pseudomonas aeruginosa*, and also polymicrobial peritonitis, fungal peritonitis, mycobacteria, and culture-negative peritonitis. As always, individual clinical situations and variability in patient populations may necessitate modification of these recommendations.

ISPD recommendations for peritonitis (Kam-Tao Li et al. 2022) provide an overview of IP antibiotic dosing recommendations for the treatment of peritonitis.

Many peritonitis episodes are mild and can be treated at home. Usually, the incubation period from time of contamination to bacterial peritonitis is 24–48 hours. Any symptoms should resolve quickly following the initiation of therapy. If the infection shows either a slow response or no response to treatment, the choice of antibiotics could be inappropriate.

Those on PD should be taught how to recognise the signs and symptoms of peritonitis during their initial training period and at regular intervals. Ideally the patient, if on CAPD, should complete the bag exchange at home (the presence of PD fluid in the peritoneum may provide some pain relief from inflammation of the peritoneal membrane) and bring the bag of cloudy dialysate effluent into the clinic for sampling. Treatment can then be initiated immediately.

There is current debate as to the necessity to perform peritoneal lavage immediately after the diagnosis of peritonitis, as it is thought to reduce the number of phagocytes present in the peritoneum that are available to fight infection. Peritoneal lavage is therefore thought by some to be of benefit only to patients with purulent effluent and abdominal pain as a pain-relieving exercise. There is no evidence to suggest that a transfer set change performed at this time is of any benefit. On admission to the PD clinic, the usual fill volume for the patient is medicated with antibiotics.

The patient or carer can be taught how to add antibiotics to the dialysis fluid to facilitate self-care. Heparin (200–500 units l⁻¹) may also be added to the fluid to prevent the formation of fibrin, which is more likely in the presence of infection.

APD patients may receive antibiotics intraperitoneally by adding the antibiotics to the daytime dwell dialysis

solution. Little is known about intermittent dosing requirements in patients treated with APD. In intermittent dosing, the antibiotic-containing dialysis solution must be allowed to dwell for at least six hours to allow adequate absorption of the antibiotic into the systemic circulation. Kam-Tao Li et al. (2022) recommends that IP antibiotics be the preferred route of administration as long as the compatibility and stability of the IP antibiotics allow unless the patient has features of systemic sepsis. IP administration is preferred because nearly 90% is absorbed in the presence of peritonitis.

Peritonitis is monitored closely, and dialysate effluent should be clear within 48 hours of commencing treatment. If the peritonitis resolves, antibiotics are discontinued 7–10 days after the start of therapy according to local protocol.

Absorption of antibiotics into the serum through the peritoneum from the dialysate is rapid. Therefore, in most cases, administration of IV antibiotics is unnecessary.

PERMEABILITY CHANGES DURING PERITONITIS

The peritoneal membrane permeability tends to increase during episodes of peritonitis, perhaps due to increased blood flow through the peritoneum. Clearances of both large and small molecules increase, as does the absorption of glucose. This can result in marked increases in protein loss through the peritoneum and poor UF. Patients need to be educated as to the need to increase dietary protein intake during episodes of peritonitis and to care for their fluid balance ensuring that, if they have no RRF, fluid intake is kept to a minimum. Peritoneal permeability to water and solutes typically increases during peritonitis. Reduced ultrafiltration may result in complication of fluid overload. It is suggested that icodextrin be considered for volume overload occurring during acute peritonitis (Kam-Tao Li et al. 2022)

Rarely, patients are severely ill with peritonitis and need to be treated in hospital.

CULTURE-NEGATIVE PERITONITIS

Occasionally (less than 20%), cultures may be negative for a variety of technical or clinical reasons. Duration of therapy should be 2 weeks. If, on the other hand, no clinical improvement occurs within 96 hours, repeat cultures should be taken with consideration of mycobacteria or fungi, and catheter replacement or removal should be considered.

FUNGAL PERITONITIS

The ISPD recommends anti-fungal prophylaxis be co-prescribed whenever patients receive an antibiotic course, regardless of the indication for that antibiotic course to prevent fungal peritonitis. There should be immediate catheter removal when fungi are identified in the PD effluent. Early catheter removal should be encouraged as this has been reported to be associated with lower mortality and a better chance of resuming PD. Anti-fungal agents should be continued after catheter removal for at least 2 weeks. Irrespective of the treatment duration, catheter reinsertion and resumption of PD have been reported after a median period of 15 weeks in less than one-third of cases. (Kam-Tao Li et al. 2022)

RELAPSING PERITONITIS

Relapsing peritonitis is diagnosed when a peritonitis episode that occurs within 4 weeks of completion of therapy of a prior episode with the same organism or one sterile (culture negative) episode (i.e., specific organism followed by the same organism, culture negative followed by a specific organism or specific organism followed by culture negative) (Kam-Tao Li et al. 2022). These infections should be treated in the same way as the initial peritonitis; however, the reason may be due to abscess formation, colonisation of the catheter, or subcutaneous catheter tunnel infection. If there is no response to the antibiotics within 96 hours, consideration should be given to catheter removal and replacement later.

EXIT-SITE AND TUNNEL INFECTION

Ming Chow et al. (2023) defines exit site infection as the presence of purulent discharge, with or without erythema of the skin at the catheter-epidermal interface. In the absence of purulent discharge, other signs of inflammation at the exit site (e.g. erythema, tenderness, swelling, granuloma, or crust formation) are insufficient to definitively diagnose exit site infection. Tunnel infection is defined as the presence of clinical inflammation (erythema, swelling, tenderness, or induration) with or without ultrasonographic evidence of a fluid collection anywhere along the catheter tunnel. Updated PD catheter-related infection recommendations were published in 2023 by the ISPD (Ming Chow et al. 2023) and provide further details.

Antibiotic therapy may be initiated immediately if the infection looks severe, or delayed until the results of the culture are available. Therapy should be continued

until the exit site appears completely normal. Prolonged antibiotics may be necessary. If 3–4 weeks of antibiotics fail to resolve the infection, the catheter may be replaced.

A peri-catheter erythema without purulent discharge can be observed from allergic skin reaction, in the setting of a recently placed catheter or following trauma to the catheter, or after a change in the dressing or cleansing materials. It can also sometimes indicate early infection warranting close monitoring for development of purulent discharge and need for antimicrobial treatment. A positive culture with a normal-appearing exit site (e.g. without purulent discharge) is indicative of colonization rather than true infection. A diagnosis of exit site infection will be based on presence of purulent discharge, with or without erythema of the skin, at the catheter-epidermal interface. A tunnel infection can present with various components of erythema, oedema, induration, or tenderness over the subcutaneous pathway, often with a peri-catheter fluid collection demonstrated using ultrasound (Ming Chow et al. 2023).

Ming Chow et al. (2023) recommends the following for monitoring and reporting catheter-related infections:

- Every programme should measure and monitor, at least on a yearly basis, the incidence of catheter-related infections.
- The rate of catheter-related infection, including organism-specific catheter-related infection, should be reported as number of episodes per year at risk.
- Suggest that exit site and tunnel infection rates, including organism-specific rates, should also be separately reported as number of episodes per year.
- Overall exit site infection rate should be no more than 0.40 episodes per year at risk.
- The proportion of PD catheter insertion-related infection within 30 days of PD catheter insertion should be less than 5% of all catheters inserted.

Systemic prophylactic antibiotics should be administered immediately before catheter insertion to prevent peritonitis, as well as the use of nasal antibiotic prophylaxis for patients identified as being nasal *S. aureus* carriers on screening prior to PD catheter insertion. Following insertion, the insertion site is covered, left undisturbed to allow wound healing and be left intact for 7 days unless soiled. This is to immobilize the new catheter and reduce the risk of infection. Start of PD is recommended at least 2 weeks after catheter insertion (Ming Chow et al. 2023).

Daily topical application of antibiotic cream or ointment (mupirocin or gentamicin) to the catheter exit

site is recommended to prevent catheter-related infection. Although it is noted that contact between ointments / creams and the PD catheter should also be minimized, as there are reports that the polyethylene glycol base in mupirocin can damage polyurethane catheters and that gentamicin cream may damage silicone catheters. Exit-site care is recommended at least twice weekly and every time after water contamination or vigorous exercise to keep clean and dry. Swimming or other water sports should preferably take place in either seawater or swimming pools that are known to be well maintained to limit exposure to waterborne pathogens. Dressing cover over the exit site is not mandatory; however, immobilization to avoid traction injury to the exit site is well recommended (Ming Chow et al. 2023)

Culture swab should be taken from an exit site with purulent discharge. Gram stain is not routinely performed unless there is drainable component. After exit-site examination, the tunnel of the catheter is to be inspected and palpated. Tenderness over the catheter pathway and drainage from the exit site after milking the track indicates tunnel infection that, if untreated, can progress to abscess formation or catheter-related peritonitis (Ming Chow et al. 2023).

Ming Chow et al. (2023) suggests that the frequency of exit site inspection and cleansing during exit site infection to be at least daily. This is to recognise the worsening of infection early, including concomitant or subsequent development of a tunnel infection. Another reason for daily care is to review the need for additional therapeutic options. Granulomas over the exit site may require additional exit-site care because it is associated with exacerbated breakdown of the exit site. Treatment options include silver nitrate cauterization, topical chlorhexidine application, and silver ion-based dressing. Silver nitrate is most commonly used but it can cause skin burns and pain.

If infection is suspected, then therapy should be initiated: this may be either intensified local care, a local antibiotic ointment, or an oral antibiotic that covers Gram-positive organisms. Ming Chow et al. (2023) recommend empiric oral antibiotic treatment of exit-site infections with appropriate *S. aureus* cover such as a penicillinase-resistant penicillin (e.g. dicloxacillin or flucloxacillin) or first-generation cephalosporin. If the patient has had a prior history of infection or colonisation with methicillin-resistant *S. aureus* (MRSA) or *Pseudomonas* species, they should receive a glycopeptide or clindamycin, or appropriate anti-pseudomonal antibiotic, respectively. It is recommended to have a minimum 2-week course of antibiotics for most catheter-related infections, except for those caused by *Pseudomonas* for which a 3-week course is recommended. Any tunnel infection should also be treated

with at least 3 weeks of effective antibiotics. Infections that fail to completely resolve following recommended antibiotic course duration is defined as refractory catheter-related infection – necessitating surgical salvage interventions or catheter removal.

There is no consensus whether routine exit site wound culture should be undertaken 1–2 weeks after completion of antibiotic treatment. However, monitoring culture after primary cure of the exit-site infection has been shown to detect persistent colonization associated with higher risks of peritonitis and transfer to haemodialysis. Removal of the dialysis catheter in patients with exit-site infections that progress to, or occur simultaneously with, peritonitis is also recommended (Kam-Tao Li et al. 2017).

For catheter infection alone, simultaneous removal and reinsertion of the PD catheter is an option to minimize PD interruptions and alleviate the need for unplanned transfer to haemodialysis. Although this has a high likelihood of resolving catheter-related infection, this procedure is subject to potential complications of a new catheter, such as peri-catheter leaks and flow dysfunction. Extrusion of the external cuff through the exit site is a mechanical complication. Over time, the tubing returns to its native straight configuration with migration of the external cuff towards the exit site. If the extruded cuff is not managed, it can become infected with bacteria and predispose to exit site infection. For those with exposed external cuff and persistent exit-site infection, removal or shaving of the external cuff can be considered when infection is limited to the exit site (Ming Chow et al. 2023). In patients who have undergone dialysis catheter removal for simultaneous exit-site or tunnel infection and peritonitis, any reinsertion of a PD catheter should be performed at least 2 weeks after catheter removal and complete resolution of peritoneal symptoms (Kam-Tao Li et al. 2017).

EDUCATION AND TRAINING FOR THOSE ON PERITONEAL DIALYSIS

It is essential that effective education takes place before patients can be expected to treat themselves at home. Upwards of 90% of the care received by home dialysis patients is self-administered in the home. ‘It is a common but erroneous belief that anyone can teach PD, but ... success depends upon the approach adopted’ (Uttley and Prowant 2000). Finkelstein et al. (2011) described components of a successful CAPD education programme based on adult learning principles. The detailed recommended practice of PD training is covered in ISPD guidelines.

Every PD programme should prepare the trainers according to this document and develop a specific curriculum for training. Unfortunately, high-level evidence guiding how, where, when, and by whom PD training should be performed is lacking (Zhang et al. 2016). Ideally, each patient should be trained by a dedicated nurse, whose time is totally focused on training the patient. However, there are few published data on the optimal nurse-to-patient ratios or training protocols (Zhang et al. 2016). It is understood that training is only one aspect of a successful PD program. Other aspects to consider are the experience of the PD nurses and nephrologists, catheter implantation technique, and environmental barriers that may impact the outcomes (Figueiredo et al. 2016).

BARRIERS TO LEARNING

People who are just about to start dialysis are often frightened – the prospect of dialysing oneself at home may not appeal. Many new patients have uraemia; symptoms may include nausea, vomiting, sleep disturbances, and confusion. Some patients feel so physically unwell by the time they are to commence dialysis that they lack the motivation to learn, feeling that they will never recover.

Teaching this group of patients can be made all the more difficult when other barriers to learning become apparent. A fundamental barrier is language, especially as growing diverse populations, give rise to the numbers of people who do not have English as their first language. There are sometimes limited resources available for translation and it can be the responsibility of a younger member of the family, often a son or daughter, to act as translator during training. This situation is not ideal because of ethical issues, and it may be difficult to ascertain who has grasped the concept or answered the question. Jargon and clinical terminology can also be frightening and confusing.

Many older patients have to learn PD and having to learn new concepts and procedures on which their life will depend may seem an overwhelming task. This sometimes makes learners feel vulnerable and inadequate, particularly if they are slow to learn. Short-term memory loss is a problem suffered by many elderly patients and is a source of great frustration to both learner and trainer. These patients frequently have added physical barriers to learning, such as poor vision or lack of manual dexterity. Varying levels of deafness may also be a problem – the learner is trying not only to understand what has been said but is also straining to hear.

Literacy levels in England are poor, with 16.5% of the population having very poor literacy skills (National Literacy Trust 2023). If we consider this challenge in

relation to the concepts and procedures that need to be explained to patients receiving dialysis, it becomes apparent that the information given must be clear, unambiguous, and readily understood, particularly if the patient's literacy difficulty is paired with a second or even a third barrier to learning.

THE LEARNING ENVIRONMENT

The main objective of home training is to establish, early on, the patient's social environment and psychological status, and to assess how these influence aspects of learning and adapting to PD. When training was individualised to the patient, Davies et al. (2000) saw in-home patient training as more efficient than in-centre training as measured by time required to train.

Figueiredo et al. (2016) identified the lack of evidence in PD training; therefore, the Nursing Liaison Committee of the International Society for Peritoneal Dialysis (ISPD) undertook a review of PD training programmes around the world in order to develop a syllabus for PD training. This syllabus was developed to help PD nurses train patients and caregivers based on a consensus of training program reviews, utilising current theories and principles of adult education. It is designed as a 5-day programme of about 3 h day⁻¹, but both duration and content may be adjusted based on the learner. After completion of the proposed PD training syllabus, the PD nurse will have provided education to a patient and/or caregiver such that the patient/caregiver has the required knowledge, skills, and abilities to perform PD at home safely and effectively. It is recommended that PD nurses review this syllabus prior to embarking on teaching patients and their families (ISPD 2023).

RECOMMENDATIONS FOR TRAINING WITHIN KIDNEY UNITS

- Set aside an area specifically for teaching purposes. The area should preferably be away from the ward and be non-clinical and quiet. A television with DVD or a desktop or laptop computer can be used in this area for teaching.
- Designate a team of nurses for training duties only. Establish some continuity of care by allocating each patient to a designated nurse.
- Invite family members or partners to participate in the teaching programme.
- Use a wide variety of training materials. Five points to good presentation of these materials:

1. Teach the smallest amount possible for the job required.
 2. Make the point as vividly as possible.
 3. Review repeatedly.
 4. Have the learner restate and demonstrate material.
 5. Make sure the subject matter is relevant.
- Any material should be presented in a way that is comprehensible to the learner.
 - Despite the fact that the readability of the material can be measured by the same formula, readers' skills may vary with their interest and background of experience in a particular topic area.
 - Training materials are most effective when presented in an interesting and appropriate manner. Both the language used and the material's degree of complexity need to be taken into account.
 - The material should be presented in a memorable fashion. Any visual aids need vivid, simple messages which are easy for patients to remember.
 - Finally, but perhaps most importantly, it is essential that the patients want to learn what is being taught.

The training programme should be designed to prepare patients fully for return to the community. The aim of the training programme is to educate patients to a standard whereby they can confidently care for themselves and perform PD in the community. For some learners this may mean that they learn only how to perform PD, troubleshoot, and manage their diet. For others, much more detail may be desired – for example, learning how dialysis works.

Group teaching is an excellent way for patients to learn. This not only enables patients to learn from each other but also helps the teacher, as many patients can be taught the same subject at the same time. Figueiredo et al. (2016) prefers that PD training courses should be taught one-on-one, nurse-to-patient, whenever possible, for consistency and ideally should be taught by the same nurse throughout the training. The nurse is expected to give undivided attention to the learner at each training session; respect the learner's preferred learning style; and be aware of his or her own preferred style of learning. The bulk of the training programme should focus on the patients themselves, relating all they are learning to their disease, treatment and, ultimately, their lifestyle. Sessions should be designed to last for no longer than 20 minutes. Visual aids such as flipcharts, acetates, and videos are used to make the material interesting and varied.

Online resources are a useful tool in the education of people with kidney disease. It provides many advantages in that the information is available 24 hours a day, 7 days a week. There are now many websites dedicated solely to the education of patients with ESKD. The following are useful additions to any training programme:

- Kidney Care UK: <https://www.kidneycareuk.org/about-kidney-health/>
- National Kidney Federation: <https://www.kidney.org.uk/Pages/Category/online-help-resources>

WHAT TO TEACH

It is important that patients new to PD are discharged from the kidney unit with enough knowledge to care for themselves safely on dialysis. Broadly speaking, when each patient is taught, priority should first be given to what they must know, then to what they should know, and finally to what they could know. However, all learning objectives should be patient centred.

The following topics should be included in a PD training programme:

- *Medication.* The patient's own medicines can be used as the central focus for this session. The aim is to ensure that the patient knows how often and why each medicine is taken.
- *Normal functions of the kidney.* This session can be given in groups using visual aids to explain in a simple way the basic functions of the kidney, relating these to the symptoms they suffer when kidneys fail.
- *CAPD and APD procedures.* These are most easily taught on a one-to-one basis. Demonstration techniques can be used to explain the procedure. A PD simulator (plastic torso with a PD catheter) is an excellent tool on which patients can practise their exchanges.
- *Catheter and catheter exit-site care.* This can be taught to the patient on a one-to-one basis. The PD simulator can be used to practise exit-site dressing technique, as can getting the patient to practise the technique in front of a mirror. Photographs are useful to help explain visually the difference between a healthy and an infected exit site.
- *How PD works.* Osmosis and diffusion can be explained using simple experiments or diagrams.
- *Diet.* Eating is an activity which most people enjoy, and which therefore takes up a rather large part of our lives. Maybe it is for this reason that many patients focus on

diet and want to know all there is to be taught. Plastic models of food can be used in training sessions to make the learning fun.

- **Infections.** It has been well documented that peritonitis is a major complication of PD. It is therefore important that peritonitis is explained to patients well, using a purpose-printed flipchart.
- **Fluid balance.** Fluid overload can be associated with excessive fluid intake and poor education. It is a common experience that one of the most difficult aspects of treatment to adhere to is the reduced fluid allowance. This subject can also be taught in groups using a purpose-printed flipchart. Weighing a jug of fluid can also be useful to demonstrate the difference between fluid weight and flesh weight.
- **Fertility and sexuality.** It is important to discuss sexuality and body image with patients on PD. Having the PD catheter present in the abdomen may inhibit some people (either the patient or partner) and it is essential that any anxieties are discussed. Fertility should also be discussed with patients and partners where appropriate, as it is possible for PD patients to conceive.
- **Employment.** Having dialysis is not a reason for giving up work. The training period is a good time to discuss work options with patients.
- **Ordering and delivery of PD supplies.** The practicalities of ordering and delivery of the PD supplies to the patient's home prove a great worry for many patients and their families. This can often be compounded by the problem of where to store this large amount of equipment. Patients can be encouraged to talk amongst themselves to gain ideas from each other as well as utilising the experience of nurses.

- **Holidays and travel.** It is possible to travel whilst being treated with PD, and many patients go on holiday frequently. The practicalities of travel and holidays should be discussed during the training period and on an ongoing basis if appropriate.
- **Exercise.** The nurse's role is to promote a healthy lifestyle for patients. The training period is an ideal opportunity to discuss which types of activities are best suited to that individual patient.

To complement the training programme, reading materials should be made available, along with posters and DVDs. Many training materials have been translated into other languages for use by those patients whose first language is not English.

Assessment of how much information the patient has retained is difficult to make accurately. Testing can be seen as a threatening procedure, even though it is essential. Games, therefore, make a valuable contribution to the task of assessing learning and can be used in a variety of forms. Simple homemade crosswords, word searches, and quizzes can be incorporated for patients and relatives to do at the end of their training.

CONCLUSION

There have been considerable advances in the delivery of PD, resulting in a cost-effective therapy, which now has equivalent – if not better – patient-reported outcomes as compared with HD (Sukul et al. 2019). Technological advances (such as APD), the ability to deliver adequate dialysis (both solute and fluid removal), and the minimisation of damage to the peritoneal membrane (biocompatible solutions, less peritonitis) will surely improve the outcome of patients in the future.

REFERENCES

- Akdam, H., Alper, A., Ozbek, O. et al. (2014). The fast peritoneal equilibrium test first and second hour results. *BANTAO Journal* 12 (1): 36–39. <https://doi.org/10.2478/bj-2014-0008>.
- Balasubramaniam, G., Brown, E.A., Davenport, A. et al. (2009). The Pan-Thames EPS study: treatment and outcomes of encapsulating peritoneal sclerosis. *Nephrology, Dialysis, Transplantation* 24 (10): 3209–3215.
- Bennett PN, Bohm C, Harasemiw O, et al. (2022). Physical activity and exercise in peritoneal dialysis: International Society for Peritoneal Dialysis and the Global Renal Exercise Network practice recommendations. *Peritoneal Dialysis International* 42 (1): 8–24.
- Boudville N and de Moraes TP. (2020) Guidelines on targets for solute and fluid removal in adults being treated with chronic peritoneal dialysis: 2019 Update of the literature and revision of recommendations. *Perit Dial Int.* 40 (3): 254–260.
- Brown EA, Bargman J, van Biesen W, et al. (2017). Length of Time on Peritoneal Dialysis and Encapsulating Peritoneal Sclerosis — Position Paper for ISPD: 2017 Update. *Peritoneal Dialysis International* 37 (4): 362–374.
- Brown EA, Ekstrand A, Gallieni M, et al. (2022). Availability of assisted peritoneal dialysis in Europe: call for increased and equal access. *Nephrol Dial Transplant.* 37 (11): 2080–2089.

- Consensus Conference on Biocompatibility (1994). *Nephrol Dialysis Transplantation* 9 (Suppl 2): 1–186.
- Crabtree JH, Shrestha BM, Chow KM, Figueiredo AE, Povlsen JV, Wilkie M, Abdel-Aal A, Cullis B, Goh BL, Briggs VR, Brown EA, Dor FJMF (2019). Creating and Maintaining Optimal Peritoneal Dialysis Access in the Adult Patient: *Perit Dial Int.* 39 (5): 414–436.
- Davies, S.J., Brown, E.A., Frandsen, N.E. et al. (2005). Longitudinal membrane function in functionally anuric patients treated with APD; data from EAPOS on the effects of glucose and icodextrin prescription. *Kidney International* 67: 1609–1615.
- Davies, S.J., Philips, L., Naish, P.F. et al. (2001). Peritoneal glucose exposure and changes in membrane solute transport with time on peritoneal dialysis. *Journal of the American Society of Nephrology* 12: 1046–1051.
- Davies, S.J., Tatchell, S., Davies, D. et al. (2000). Routine peritoneal dialysis training in the home: extending community treatment. *Peritoneal Dialysis International* 20: S83.
- Figueiredo, A., Bernardini, J., Bowes, E. et al. (2016). A syllabus for teaching peritoneal dialysis to patients and caregivers. *Peritoneal Dialysis International* 36: 592–605.
- Finkelstein, F.O., Ezekiel, O., and Raducu, R. (2011). Development of a peritoneal dialysis program. *Blood Purification* 31 (1–3): 121–124.
- Galallah, M.F., Ramdeen, G., Mignone, J. et al. (2000). Role of pre-operative antibiotic prophylaxis in preventing post operative peritonitis in newly placed PD catheters. *American Journal of Kidney Disease* 36 (5): 1014–1019.
- Gotch, F.A. and Sargent, J.A. (1985). A mechanistic analysis of the National Co-operative Dialysis Study (NCDS). *Kidney International* 28: 526–534.
- Gotch, F.A., Sargent, J.A., Parker, T.J. et al. (1983). National co-operative dialysis study: comparison of the study groups and a description of morbidity, mortality, and patient withdrawal. *Kidney International* 26 (suppl. 23): S42–S49.
- Gotloib, L. (2009). Functional structure of the peritoneum as a dialyzing membrane. In: *Nolph and Gokal's Textbook of Peritoneal Dialysis* (ed. R. Khanna and R.T. Krediet), 73–135. Boston, MA: Springer.
- Ikizler T.A., Burrowes J.D., Byham-Gray, L.D., et al. (2020). KDOQI clinical practice guideline for nutrition in CKD: 2020 update. *Am J Kidney Dis.* 76 (3 suppl 1): S1–S107. doi: 10.1053/j.ajkd.2020.05.006.
- International Society for Peritoneal Disease (ISPD) (2023). Adult ISPD guidelines. <https://ispd.org/ispd-guidelines> (accessed 23 November 2023).
- Johnson, D.W., Cho, Y., Livingston, B.E.R. et al. (2010). Encapsulating peritoneal sclerosis: incidence, predictors, and outcomes. *Kidney International* 77 (10): 904–912.
- Li, PK-T., Chow, K.M., Cho, Y., et al. (2022). ISPD peritonitis guideline recommendations: 2022 update on prevention and treatment. *Peritoneal Dialysis International*. 42 (2): 110–153.
- Lipkin, G. and McKane, W. (2021). *The Renal Medicine Getting It Right First Time (GIRFT) Programme National Specialty Report* (London: NHS). <https://ukkidney.org/sites/renal.org/files/Renal%20Medicine%20Sept21k.pdf> (accessed 23 August 2023).
- Kendrick, J. and Teitelbaum, I. (2010). Strategies for improving long-term survival in peritoneal dialysis patients. *Clinical Journal of the American Society of Nephrology* 5 (6): 1123–1131.
- Lin, A., Qian, J., Li, X. et al. (2009). Randomized controlled trial of icodextrin versus glucose containing peritoneal dialysis fluid. *Clinical Journal of the American Society of Nephrology* 4 (11): 1799–1804.
- Lokesh, S. and Arun Kumar, R. (2013). Better understanding of peritoneal membrane anatomy and physiology—a success behind peritoneal dialysis. *International Journal of Current Microbiology and Applied Sciences* 2 (8): 144–147.
- Morelle, J., Stachowska-Pietka, J., Öberg, C., et al. (2021). ISPD recommendations for the evaluation of peritoneal membrane dysfunction in adults: Classification, measurement, interpretation and rationale for intervention. *Peritoneal Dialysis International* 41 (4): 352–372.
- Mushahar, L., Mei, L., Yusef, W., et al. (2016). Exit site dressing and infection in PD: A randomized controlled pilot trial. *Peritoneal Dialysis International*. Mar–Apr 36.
- Nadeau-Fredette, A.C. and Bargman, J.M. (2015). Characteristics and outcomes of fungal peritonitis in a modern North American cohort. *Peritoneal Dialysis International* 35: 78–84.
- National Institute for Health and Care Excellence (2018). Renal Replacement Therapy and Conservative Management. (Guideline 107) <https://www.nice.org.uk/guidance/ng107>.
- National Literacy Trust (2023). <https://literacytrust.org.uk> (accessed 27 November 2023).
- Paniagua, R., Amato, D., Vonesh, E. et al. (2002). Effects of Increased Peritoneal Clearances on Mortality Rates in Peritoneal Dialysis: ADEMEX, a Prospective, Randomized. *Controlled Trial. JASN May* 13 (5): 1307–1320. <https://jasn.asnjournals.org/content/13/5/1307/tab-article-info>.
- Plum, J., Hermann, S., Fusshöller, A. et al. (2001). Peritoneal sclerosis in peritoneal dialysis patients related to dialysis settings and peritoneal transport properties. *Kidney International* 59 (suppl 78): S42–S47.
- Quellhorst E. Insulin therapy during peritoneal dialysis: pros and cons of various forms of administration (2002). *Journal of the American Society of Nephrology* 2002;13 (suppl 1): S92–S96. doi: 10.1681/ASN.V13suppl_1s92.
- Selgas, R., Bajo, M.A., Paiva, A., et al. (1998). Stability of the peritoneal membrane in long-term peritoneal dialysis patients. *Advances in Renal Replacement Therapy* 5: 168–178.
- Silver, S., Harel, Z., and Perl, J. (2014). Practical considerations when prescribing Icodextran: a narrative review. *American Journal of Nephrology* 39: 515–527.
- Sukul, N., Zhao, J., Fuller, D.S., et al. (2019). Patient-reported advantages and disadvantages of peritoneal dialysis: results from the PDOPPS. *BMC Nephrology* 20, 116. <https://doi.org/10.1186/s12882-019-1304-3>

- Twardowski, Z.J. and Nichols, W.K. (2009). Peritoneal dialysis access and exit site care including surgical aspects. In: *Nolph and Gokal's Textbook of Peritoneal Dialysis*, 3e (ed. R. Khanna and R.T. Krediet), 307–361. Boston, MA: Springer.
- Uttley, L. and Prowant, B. (2000). Organisation of a CAPD programme – the nurse's role. In: *Textbook of Peritoneal Dialysis* (ed. R. Gokal, R. Khanna, R. Krediet, et al.), 363–386. Dordrecht: Kluwer.
- Van Biesen, W., Heimbürger, O., Krediet, R. et al. (2010). Evaluation of peritoneal membrane characteristics: clinical advice for prescription management by the ERBP working group. *Nephrology, Dialysis, Transplantation* 25 (7): 2052–2062.
- van Eck van der Sluijs A, van Jaarsveld BC, Allen J, et al. (2021). Assisted peritoneal dialysis across Europe: Practice variation and factors associated with availability. *Perit Dial Int.* 41 (6): 533–541.
- Wijewickrama, P., Williams, J., Bain, S., et al. (2023). Narrative Review of Glycemic Management in People with Diabetes on Peritoneal Dialysis. *Kidney International Reports* 8 (4): 700–714. doi: 10.1016/j.ekir.2023.01.040
- Woodrow, G., Fan, S., Reid, C. et al. (2017). *Clinical Practice Guideline Peritoneal Dialysis in Adults and Children*. UK Kidney Association.
- Zhang, L., Hawley, C.M., and Johnson, D.W. (2016). Focus on peritoneal dialysis training: working to decrease peritonitis rates. *Nephrology, Dialysis, Transplantation* 31: 214–222.

ADDITIONAL RESOURCES

ISPD Teaching nurses to teach. <https://ispd.org/teaching-nurses/> (accessed 28 August 2023).

ISPD Guidelines. <https://ispd.org/guidelines/> (Accessed 28 August 2023).

UK Kidney Association Clinical Practice guidelines for Peritoneal Dialysis Access. <https://ukkidney.org/sites/renal.org/files/UKKA%20PD%20access%20guidelines%20-%20final%20site%20version.pdf> (accessed 24 August 2023).

LEARNING OUTCOMES

- to discuss the risks and benefits of kidney transplantation.
- to identify the contraindications to kidney transplantation.
- to understand the importance of pre-transplant assessment and the nursing role in the pre-transplant clinical care pathway.
- to explore donor and recipient matching and its relevance to graft survival.
- to understand deceased and living donation.
- to critically evaluate the possible options to increase deceased donor supply.
- to outline the nursing care for the kidney transplant recipient in the pre-, peri-, and post-operative stage.
- to explain the use of immunosuppressive regimens in individual recipients.

INTRODUCTION

Kidney transplantation is now widely acknowledged as the treatment of choice for those with end-stage kidney disease (ESKD). Since the time of the first transplants in the 1950s, advances in antirejection therapies, surgical techniques, and tissue matching have enabled kidney transplantation to evolve from an experimental procedure to the treatment that can offer good quality of life and the most cost-effective care for patients with kidney disease.

A successful transplant offers freedom from the practical and psychological difficulties and restrictions of long-term dialysis; freedom from dependence on a machine or fluid bag; freedom from fluid and dietary restrictions; a return of sexual functioning and fertility with the possibility of parenthood; and a return to an almost normal lifestyle.

Most research studies clearly show that for the majority, kidney transplantation has the greater rehabilitation potential and that the quality of life for patients with functioning grafts is superior to that which is usually achieved on dialysis (Kaballo et al. 2018; Chaudhry et al. 2022). Research into quality of life has received much criticism, and individual perception and assessment of quality of life is known to be affected by a wide range of independent and personal variables. However, for many

of those with renal failure, transplantation offers an improved quality of life and may be the most significant factor for patients when considering transplantation.

COST-EFFECTIVE CARE

Transplantation is the most cost-effective treatment option for ESKD. The cost of a year of haemodialysis or peritoneal dialysis is similar to that of a kidney transplant in the first year. However, thereafter the cost of continuing care for a patient with a transplant is one-fifth of the cost of dialysis per year (NHS England 2017).

UK NATIONAL WAITING-LIST FIGURES FOR KIDNEY TRANSPLANT

The improvements in quality of life and cost-effectiveness of transplantation support the suggestion that kidney transplantation is the treatment of choice for the majority of patients. Unfortunately, such a goal is not currently possible because of the limited supply of deceased donor organs. The current UK waiting list for kidney transplantation stands at just under 5000 patients (Figure 9.1). In 2021–2022 in the UK, 3152 kidney transplants were performed (National Health Service NHS Blood and Transplant [NHSBT] 2022a).

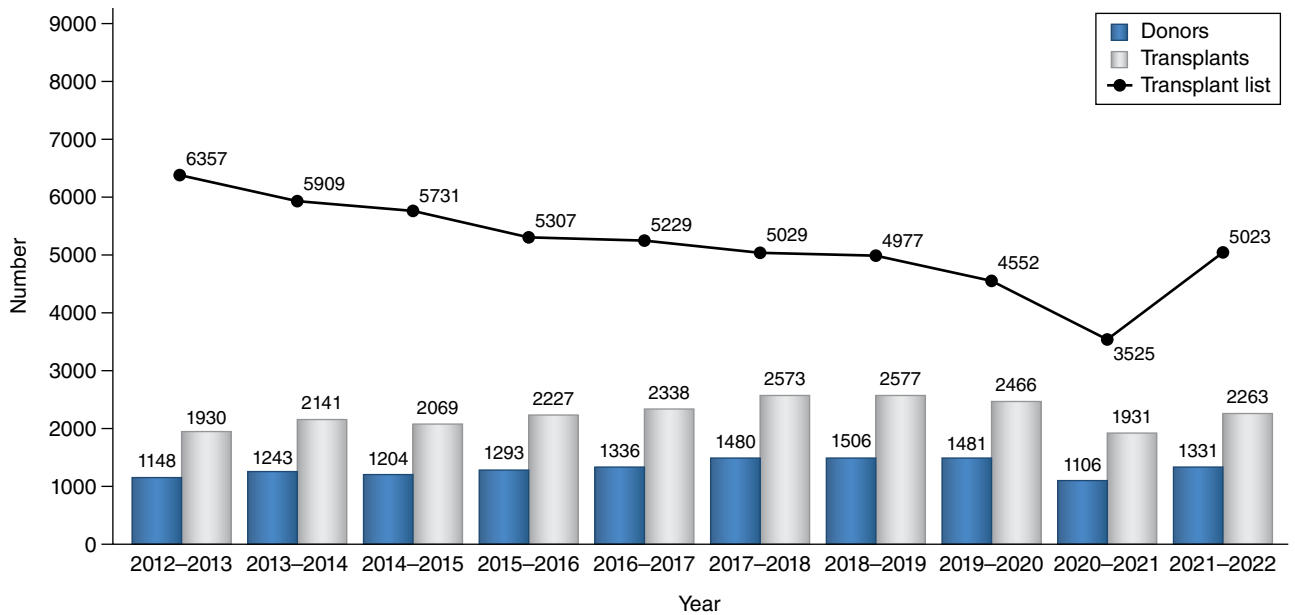


FIGURE 9.1 Deceased donor kidney programme in the United Kingdom, 1 April 2012–31 March 2022. Number of donors, transplants, and patients on the active transplant list on 31 March. *Source:* from *Transplant Activity in the UK 2021–2022*, NHS Blood and Transplant.

We therefore need to explore ways of increasing donor numbers in order to offer all suitable patients the chance of a transplant.

CONTRAINDICATIONS TO KIDNEY TRANSPLANTATION

Although the majority of patients may request a transplant, transplantation is not suitable for all those with ESKD because of possible medical complications.

MALIGNANCY

Malignant disease must be excluded prior to transplantation as the immunosuppressive regime may accelerate growth of the malignancy and encourage secondary spread. If the patient is known to have had cancer in the past, it is important to ascertain the type of malignancy, the stage of development, and the treatment received. Transplantation may still be possible, provided that curative treatment has been given and sufficiently long follow-up has occurred to exclude recurrence. Recurrence risk from cancer post-transplant is thought to be lower than previously reported, at around 10%, but is

associated with worse outcomes post-transplant and increased cancer related mortality (Schrieber et al. 2022). Guidelines differ in recommending disease-free periods to transplantation, ranging from 2 to 5 years, depending on the type of malignancy (Batabyal et al. 2012).

Waiting time prior to listing can be stratified based on the type and stage of cancer diagnosed and clinicians are advised to balance the risk of cancer recurrence against the risk of mortality on dialysis after full counselling and discussion with the recipient (Chadban et al. 2020).

RECURRENT DISEASE

It is important to consider the patient's primary kidney disease, as in some cases the disease may recur and destroy the new kidney. Renal disorders with a high recurrence rate include primary focal segmental glomerulosclerosis (FSGS) (causing massive proteinuria and scarring of the glomeruli), membranoproliferative glomerulonephritis (an immunological disorder of the glomeruli), and IgA nephropathy (IgAN). Recurrence of primary disease can occur in up to 20% of patients after transplant and can lead to graft loss in around 9% of patients (Chadban et al. 2020).

Transplantation can still be considered but only after counselling and explanation of the risks to the patient. Many centres would advise against living related donation in this situation; however, it may still be possible providing both donor and recipient are fully aware of the risk of recurrence.

In some conditions, such as FSGS, C3 glomerulopathy, and atypical haemolytic uremic syndrome (aHUS), genetic testing can be helpful in identifying the risk of recurrence post-transplant and in some cases ensuring access to treatments post-transplant should this recur. However, all conditions should be fully investigated prior to transplantation to ensure that the cause is treated and the disease is quiescent.

In other conditions, such as lupus nephritis, ANCA vasculitis, and anti-GBM disease, disease should be quiescent and the patient receiving minimal or no immunosuppression before transplantation can be considered.

Several other diseases, such as diabetes, can cause microscopic changes in the kidney after many years but rarely lead to graft loss.

HEPATITIS VIRUS AND HUMAN IMMUNODEFICIENCY VIRUS

Patients who are hepatitis B or hepatitis C positive may be at risk of progressive liver disease after transplantation due to the impact of the immunosuppressive therapy. Consultation with a hepatologist may be required and possibly liver biopsy to determine activity of the virus and presence of liver damage. Many patients who are hepatitis B or C positive have no disease or quiescent disease and are therefore suitable for transplantation. Careful monitoring in this group of patients is required after transplant to ensure early detection of increased viral activity and to ensure antiviral therapy is continued at appropriate doses. Previously, infection with human immunodeficiency virus (HIV) was considered an absolute contraindication to transplantation, but the use of combination antiretroviral therapy (cART) and careful recipient selection has made transplantation possible in this group of patients. Studies have shown comparable survival outcomes in HIV-positive recipients compared to HIV-negative recipients (Roland et al. 2016, Muller et al. 2021). HIV disease should be suppressed prior to proceeding to transplantation with stable medication regimen and no recent opportunistic infections (Chadban et al. 2020).

DIABETES MELLITUS AND CARDIOVASCULAR DISEASE

Diabetes is the second most common cause of ESKD in the UK and is more prevalent in those aged over 65; survival of those with diabetes is worse than those without diabetes

when both are receiving kidney replacement therapy (KRT) (MacNeill et al. 2016). Further to this, evidence in the literature suggests that outcomes for patients with diabetes after transplantation are worse than for others. Guidelines recommend that potential transplant recipients with diabetes should not be excluded from assessment but the recommendation is for enhanced screening for cardiovascular risk at the assessment stage (Chadban et al. 2020).

The death rate from cardiovascular disease is known to be approximately 15 times higher in patients receiving dialysis than those in the general population and is a significant cause of mortality in kidney transplant recipients (Jankowski et al. 2021, UK Renal Registry 2023).

EVALUATION FOR TRANSPLANTATION

AGE

Morbidity and mortality after kidney transplantation tend to increase with age, and therefore the age of the recipient must be classed as a risk factor. Age must also be considered within the context of other risk factors, such as advanced cardiovascular disease and diabetes mellitus. There is no age barrier for transplantation; health is assessed on an individual basis, and physiological rather than chronological age and the existence of other risk factors are seen as the important assessment issues. Many units have patients of 70 years and over who have progressed well following a kidney transplant, and transplant recipients of all ages report improved quality of life after transplant when compared with those still on the waiting list (Gibbons et al. 2020).

However, with demand far exceeding supply and studies reporting uncertain survival benefit after transplantation in the older recipient (Chaudhry et al. 2022) some may question the use of a limited resource in this group (Box 9.1).

POLYCYSTIC KIDNEY DISEASE

This inherited kidney disease can result in several members of a family receiving ESKD therapies. The native cystic kidneys may be very large, thus leaving little space for the transplant, and there may also be an increased risk of bleeding and infection. It may be necessary to perform a unilateral, or in severe cases a bilateral, nephrectomy prior to listing for transplantation.

URINARY TRACT DISEASE

It is important to assess that there are no problems with the bladder and urethra and that there will be no difficulties following transplantation; if it is felt that the

BOX 9.1**ETHICAL DISCUSSION POINT
ON SHORTAGE
OF DONOR ORGANS**

- Demand for kidney transplants far exceeds supply.
- Younger patients are shown to gain greater life expectancy after a transplant.
- Older patients are at greater risk of complications.

Both groups report improved quality of life after transplantation.

Discussion

- Should younger patients be given priority over the older group?

bladder capacity is unacceptably low, surgical enlargement may be possible. In the presence of a history of repeated urinary tract infections with bilateral reflux, it may be necessary to undertake a bilateral nephrectomy prior to transplantation to reduce the risk of post-transplant infection.

CARDIAC DISEASE

Routine investigations such as an electrocardiogram (ECG) and echocardiogram and a cardiac history are essential for all patients undergoing assessment for transplantation. Those patients who are in the high-risk groups for cardiovascular disease (e.g. older patients and those with diabetes) should undergo more extensive assessment and may require referral to a cardiologist. There is currently no evidence that more extensive investigation and assessment in this group is predictive of risk of cardiac events at time of transplant (Wang et al. 2015).

PEPTIC ULCERATION

A history of indigestion and/or peptic ulceration must be noted and endoscopy undertaken if active ulceration is a possibility, as those with active ulceration risk bleeding after transplantation due to the action of the steroid therapy. If active *Helicobacter pylori* is present, treatment with a proton pump inhibitor (PPI) in combination with antibiotics should be given prior to transplantation. Many centres also use PPI as prophylaxis in all recipients during the first 3–6 post-operative months.

RESPIRATORY DISEASE

Pulmonary tuberculosis will require treatment before listing for transplantation. Patients with a history of tuberculosis and those who have visited or lived in high-risk areas will require prophylaxis with isoniazid for at least a year following transplantation.

Patients should also be strongly advised to stop smoking and should be offered information regarding smoking cessation strategies and support systems.

OBESITY

Obesity may make the transplant surgery difficult and increases the risk of post-operative complications. However, NICE guidance (2018) states that ‘people should not be excluded from receiving a kidney transplant based on BMI alone’.

Nutritional advice should be given before and after transplantation (see Chapter 12).

ORAL HYGIENE

Dental hygiene and assessment of dental state are essential. Any gum infection or dental problems should be dealt with prior to transplantation. Calcineurin inhibitors (CNIs) can cause gum hypertrophy, which is made much worse in the presence of poor dental hygiene.

PRE-TRANSPLANTATION PREPARATION

Patients may be referred for transplantation during different phases of the disease process; some may be in the pre-dialysis stage, others may already be established on dialysis therapy. UK guidelines allow a patient to be listed on the deceased donor list once he/she is within approximately six months of requiring dialysis (eGFR of $<15 \text{ ml min}^{-1}$). A pre-emptive transplant gives a better outcome compared to having to spend time on dialysis. Evidence suggests that pre-emptive transplantation leads to improved graft survival compared with transplantation after dialysis, with longer time spent on dialysis leading to worse outcomes in terms of graft survival, mortality, and infection (Naylor et al. 2022).

A planned pre-emptive transplant from a living donor gives the best outcome in terms of graft success and recipient health. Early transplantation before the need for dialysis therapy is welcomed from a clinical perspective but may prove difficult psychologically if emotional

adjustments have not been successfully negotiated and the patient and family are still reeling from the impact of the disease. A structured approach to pre-dialysis education and counselling should include discussion of suitability for transplantation, and the likelihood of any potential living donors being found. Suitable patients can then be seen for pre-transplant education and assessment, and friends or relatives who are interested in living donation can be contacted at this early stage. An overview of the psychological support required prior to transplantation is outlined in Chapter 4.

Boxes 9.2–9.4 show useful checklists for the pre-transplant stage. Pre-transplant assessment is usually a multidisciplinary process, involving medical, surgical, and specialist nurse input. A systematic approach to assessing patients for suitability for transplantation should include those approaching ERF as well as those on dialysis. This is of particular importance when a suitable living donor may be found, thus allowing pre-emptive transplantation.

SPECIFIC PRE-TRANSPLANT ANXIETIES AND FEARS

Specific issues concerning body image are discussed in Chapter 4; other anxieties include acceptance of the transplant as part of the 'self' and guilt over benefiting from

traumatic death. There are also very specific challenges relating to patients' education and understanding of their immunosuppressive therapy.

It is vital that patients understand the need to continue with their antirejection therapy for as long as they have their transplant. Many patients believe that it will only be necessary to take the drugs until the kidney settles into the body. There are great challenges for the transplant team to ensure that patients are well informed about their medication.

Previous reviews have highlighted several factors related to non-adherence to treatment after transplant. These included: age (50 years and younger), male, lack of social support, unemployment, multiple co-morbidities, multiple medications, and psychosocial issues (such as anxiety and depression) (Belaiche et al. 2017). More recent reviews have highlighted the difficulty in defining and diagnosing non-adherence (Sumit et al. 2020).

It is inappropriate to refuse transplantation to patients who are perceived as high risk for non-adherence. It is important to offer extensive pre-transplant counselling to explore the reasons for not taking healthcare advice and to ensure additional post-transplant support is available to facilitate adherence to medication therapies. This may necessitate changing to an immunosuppression regime

BOX 9.2

PRE-TRANSPLANT INFORMATION AND ASSESSMENT CHECKLIST USED BY THE TRANSPLANT NURSE SPECIALIST: INFORMATION AND DISCUSSION

1. Desire to receive a transplant.
2. Benefits of a kidney transplant:
 - Improved quality of life
 - Freedom from dialysis
 - Freedom from fluid and dietary restrictions
 - Freedom to travel (advise to wait until one year post-transplant before travelling abroad)
 - Employment
 - Improved fertility (majority) – contraception
3. Risks/disadvantages of a kidney transplant:
 - Immunosuppression
 - Adherence with medication and healthcare advice, frequent clinic attendance
 - Drug side effects
 - Susceptible to infections and viruses
 - Lymphoma and cytomegalovirus (cmv) infection – risks and treatment
 - Risk of rejection/biopsies
4. Practical information
 - Orientation
 - Waiting list
 - Planning for the transplant call
 - Transplant call
 - Contact numbers
 - Inpatient care
 - Pre- and post-operative care
 - Transplant nurse specialist
 - Tour of the transplant unit
 - How it works, how to manage waiting time
 - Arrange child/pet/others care
 - What to expect, transport arrangements
 - Holiday arrangements
 - What to expect, discharge arrangements, follow-up
 - Contact card – further contact

BOX 9.3**PRE-TRANSPLANT INFORMATION AND ASSESSMENT CHECKLIST USED BY THE TRANSPLANT NURSE SPECIALIST: CLINICAL INFORMATION AND INVESTIGATIONS**

1. Blood group
2. Tissue typing
3. Biochemistry
4. Haematology
5. Liver function tests
6. Lipid levels
7. Virology screen:
 - Hepatitis B and C virus
 - CMV
 - HIV
 - Epstein–Barr virus (EBV)
 - Varicella Zoster virus (VZV)
 - Human T cell lymphotropic virus (HTLV) 1 and 2
8. Infection screen:
 - Methicillin Resistant *Staphylococcus aureus* (MRSA)
 - *toxoplasma gondii*
 - *treponema pallidum* (syphilis)
9. Midstream urine
10. Further specific investigations as required

Clinical information

- Dental check: date of last check
- Female patients: last cervical smear; date of last smear and result
- Breast self-examination; date and results of last mammogram if applicable
- Weight
- Height
- Body mass index

BOX 9.4**PRE-TRANSPLANT INFORMATION AND ASSESSMENT PROFORMA: CLINICAL ASSESSMENT CHECKLIST USED BY THE PHYSICIAN/SURGEON TO EVALUATE CLINICAL ASSESSMENT AND INFORMATION****Clinical history**

1. Kidney disease and disease progression: dialysis status
2. Previous medical history, noting previous blood transfusions, pregnancies, and previous transplants
3. Previous surgery
4. Current clinical status
5. Social history, family status
6. Smoking, alcohol, recreational drugs
7. Current medications, allergies
8. Immunological status, blood group

Clinical assessment

1. Cardiac assessment, including baseline echocardiogram and ECG
2. Respiratory assessment, tuberculosis risks/contacts
3. Urological assessment
4. Abdominal assessment – previous surgery, Tenckhoff site

5. Vascular assessment – assess pulses

6. Dentition
7. Gynaecological status

Information: discussion

1. Risks
 - Surgical, anaesthetic, patient survival rates
 - Graft survival rates – deceased and living donor
 - Lymphoma
 - CMV
 - Cardiovascular
 - Skin cancer
2. Further investigations required
3. Live donor possibility or deceased donor list
4. Immunosuppression regimen required
5. Decision
 - On deceased donor transplant waiting list
 - Living donor programme
 - Awaiting further investigations and/or referral
 - Patient undecided – does not want a transplant
 - Unsuitable for transplant due to ...

with a different side effect profile. Close monitoring of immunosuppressant levels and ensuring attendance at clinic visits are vital.

TRANSPLANT WAITING LIST

Once the pre-transplant assessment has been completed satisfactorily and the tissue-typing and blood-group details are finalised, the name of the patient will be added to the national waiting list. Waiting time is impossible to predict, but there are tools available that can estimate waiting times for patients based on factors such as blood group, and human leukocyte antigen (HLA) type. These are available for patients and clinicians at the ‘Tools, policies and guidance’ section at the ODT Clinical website (ODT Clinical 2023).

It is important to explain to patients that the transplant waiting list is very different from other hospital waiting lists in that they do not simply have to wait until their name reaches the top to receive a graft. The transplant list is essentially a pool of recipients, and each transplant is allocated on the basis of the closest match. Therefore, their name will join the recipient pool and they must wait for the best match for them. This is a difficult concept to understand, and some patients become distressed if another patient, who has waited less time, is transplanted before them.

It is also important that patients do not sit by the phone all day waiting for ‘the call’, thus greatly restricting their lifestyle. Patients are encouraged to keep as active and as healthy as possible whilst waiting and to continue a normal lifestyle. Some patients may still feel ambivalent about a transplant at this time. Specific fears and anxieties may need to be explored and support given within the context that patients must be allowed the time to decide the best treatment for themselves. Ongoing contact with the transplant nurse specialist is vital during the waiting time, and it is recommended that those who are waiting are contacted every 12 months and offered support and reassurance. Support is especially important at times of additional stress such as when a fellow dialysis patient receives or rejects a kidney.

DONOR AND RECIPIENT MATCHING

IMMUNE SYSTEM: OVERVIEW

The human body has a complex system of defenses that can provide protection against infection and disease. This system has the ability to target, isolate, and destroy potentially harmful invaders. This destruction is achieved in three stages – first by the recognition of structures on the invader (antigens), which are not present in the host. Antibodies and T cells that can recognise the antigens as

‘foreign’ are then produced. These antibodies and T cells then attach to the invader and destroy it both directly and by recruiting other mechanisms of destruction. Exactly the same happens to a transplant unless it is from an identical twin. The ‘foreign’ antigens on the transplant induce antibodies and T cells. These target the transplanted organ and do their very best to destroy it. The term *transplant antigens* is used to describe those antigens that are most important in this regard. Only two are really important: the HLA system and the ABO system (see below). In order to prevent rejection, it is necessary to circumvent the immune system (by matching and cross-matching) and to suppress the immunological response.

COMPONENTS OF THE IMMUNE SYSTEM

Leukocytes (white blood cells)

These comprise the cells that produce the antibody (B lymphocytes), recognise the foreign antigens (T lymphocytes), directly destroy invaders (activated T lymphocytes), or can be called in to help with the destruction process (monocytes, polymorphs, and eosinophils). Thus, it can be seen that the lymphocytes play several roles and therefore have the major influence on graft acceptance.

Lymphocytes

These comprise 20% of the total white blood cell count and are made up of several groups of cells with specialised functions. The term *orchestra* is often used to describe the mode of operation. Each section of the orchestra is made up of individuals with similar but not identical characteristics. The overall result of the orchestra playing is a result of each section performing in concert with the others.

There are two types of lymphocytes:

- *T cells*: These have antigen recognition structures fixed to their surface.
- *B cells*: These have antigen recognition structures that can be secreted (antibodies).

T cells and B cells can be naive or activated. T cells can be activated to various functions, namely helper, killer, or tolerant status. B cells can be activated to produce antibody or memory.

Each naive lymphocyte has a unique antigen recognition structure – for example, different from other members of its section and thus capable of seeing a different antigen. In this way, literally millions of ‘foreign’

antigens can be recognised. Each time a recognition event occurs, a naive cell becomes activated and divides. Thus, even if a single cell recognises an antigen as foreign, it keeps dividing until it forms a significant number of identical cells (a clone), all capable of recognising the antigen.

Depending on influences from other sections, T cells can help B cells produce antibodies (helper T cells), kill targets bearing the antigen directly (killer T cells), or become tolerant (i.e. capable of recognising the antigen but not producing a damaging response to it). B cells can produce antibodies in around 8–10 days if they see it for the first time (naive B cells) or within 24 hours if they have seen it before (memory B cells). B cells produce much more antibody if they get help from the T cells, which can themselves see the same antigen.

One point about antibody production that is relevant to transplantation is that the process that produces it is long lived. This is very positive for vaccination programmes, where having antibody around for years and years is very beneficial, although negative of course for transplantation.

ABO blood groups

The ABO system of human blood groups was described by Landsteiner in 1902. Blood group is determined by A and B antigens on the surface of the red blood cells. Each individual has one of the four basic blood group types – O, A, B, or AB.

Each individual has antibodies to the blood group antigens that they do not express (Table 9.1). Antibodies against the blood group antigens can cause hyperacute rejection and therefore matching of blood group between donor and recipient is vital. Blood group O organs can be transplanted into all groups; O is classified as the universal donor. Blood group AB recipients can receive organs from all groups; AB is classified as the universal recipient. A small proportion of people with group A belong to a subgroup defined as A2 and have reduced expression of A antigen. These kidneys may be successfully transplanted into O or B, or A2B into AB, recipients with low anti-A titres (Bryan et al. 2007).

Recent advances in pre-transplant care have allowed transplants to take place between a blood group incompatible (ABOi) donor and recipient. Such programmes are suitable only for living donor transplants due to the pre-transplant treatment required for the recipient. Antibodies can be removed from the recipient using various strategies, including plasmapheresis and immunoadsorption. More potent immunosuppressive medications may also be required. This strategy allows transplants to take place between donor and recipient pairs that would previously have been unsuitable, thus increasing the chance of transplantation for many recipients. The risk of rejection of the transplant, failure of the graft, and of serious side effects of immunosuppression are higher than with a blood group compatible transplant. It is important that recipients of this type of transplant are fully informed of the risks prior to undertaking this procedure.

Histocompatibility antigens

A further set of proteins that can trigger the B and T cell response are the transplantation antigens or the histocompatibility antigens. The histocompatibility antigens can be divided into two groups – major and minor.

Major histocompatibility complex

This system, first discovered in the mouse by Peter Gorer at Guy's Hospital in the late 1930s, is, as the name suggests, the most important system in transplantation and indeed in immunity to infection. The human system is termed HLA and was first identified in the 1960s. The sera from pregnant women were found to have antibodies that recognised lymphocytes from their partners and from some random blood donors. The reason for this is that pregnancy is in some ways like a transplant. Passage of blood from partner or child to mother results in T cells and antibody being produced to the foreign antigens on the blood cells. Since the most potent foreign antigens are those of the HLA system, most of the mother's response is directed against them and the long-lived antibody-producing cells

Table 9.1 The ABO blood group system.

Blood group	Percentage of population	Antigens expressed	Antibodies expressed	Acceptable donor blood group
O	47%	None	Anti-A, Anti-B	O
A	42%	A	Anti-B	O, A
B	8%	B	Anti-A	O, B
AB	3%	AB	None	O, A, B, AB

remain in her blood. These antibodies can persist for over 40 years.

The HLA system is complex. There are four main series important for transplantation – A, B, C, and DR. There are over 30 antigens in each series. Each person can have two from each series (one from each parent). The permutation on 2/30 from A, 2/30 from B, 2/30 from C, and 2/30 from DR means that, outside a family, it is very rare for individuals to have identical HLA types. Luckily for matching in kidney transplantation, DR is dominant. However, most of the antibody and T-cell response is produced to A, B, and C.

The rules for HLA and matching are not nearly so clear-cut as the rules for ABO, but there are several strong guidelines:

- Transplantation of a kidney into someone who has antibodies directed to a foreign (mismatched) HLA antigen on that kidney will result in hyperacute rejection.
- Transplantation of a kidney into someone who has strong memory to a foreign (mismatched) HLA antigen on that kidney will result in very rapid rejection.
- Transplantation of a kidney with two mismatches at DR will have more rejection than one with no mismatch at DR. However, rejection episodes can be treated or mismatched patients given additional immunosuppression. The total number of mismatches has a bearing on long-term outcome (Figure 9.2).

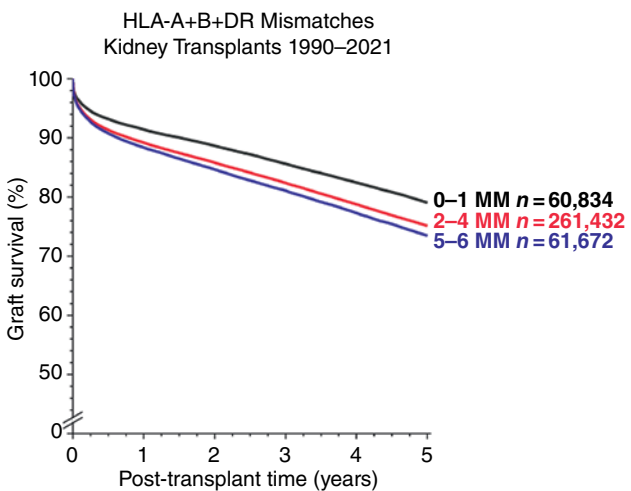


FIGURE 9.2 Influence of human leukocyte antigen (HLA) matching on renal allograft survival. *Source:* CTS (2023). MM = mismatch.

REQUIREMENTS FOR DONOR AND RECIPIENT MATCHING

The majority of organs for transplant come from deceased donors. It is essential to match for blood group and to achieve the best DR match possible. Since antibodies can be induced to pregnancies, transfusions, or previous transplants and can be boosted by infection, regular screening of patients on the waiting list is necessary to maintain knowledge of their current antibody status. Donors are avoided if they contain any mismatch to which the recipient has antibodies in current or recent serum.

Pre-transplant cross-match

Immediately prior to transplant a cross-match test is performed in the tissue-typing laboratory. A recent blood sample and selected past samples from the recipient are checked against donor lymphocyte cells. If the donor cells react (die), the result is termed a positive cross-match; the recipient is adversely reacting to the donor antigens. In the presence of a positive cross-match, transplantation cannot proceed, as the transplant would be rejected.

Traditionally a cross-match was performed prior to deceased donor transplantation and the results were obtained before the transplant operation could proceed. Recognition of the significance of shorter cold ischaemic times (CIT) in improved short-term graft success rates has led to the introduction of virtual cross-matching. In this situation, the transplant proceeds without completing a traditional prospective cross-match. This can only occur if the recipient has had regular blood samples sent to the laboratory for antibody testing prior to the transplant. Careful history should be taken at time of transplant to ensure the recipient has not received any recent blood transfusions that would affect antibody status. Recipients known to be sensitised (i.e. with a high level of HLA antibodies to a potential donor) would not necessarily be suitable for this technique, but some transplant centres are suggesting it may be feasible due to the reliability of cross-matching techniques. These recipients would also then gain the benefits of potentially shorter CIT (Jaramillo et al. 2020).

Sensitisation

When there is a positive cross-match, the recipient is sensitised to that donor. The higher the level of sensitisation, the greater will be the difficulty in finding a transplant that will not reject.

Sensitisation can occur during pregnancy (to partner’s antigens), during blood transfusion, and after

transplantation. In order to reduce the risk of sensitisation it is important to minimise the giving of blood transfusions.

Some recipients may have a high level of sensitisation. The patient's serum is tested periodically against the HLA types of 10,000 donors on the national database. If the patient does not react with the various donors tested then they are classified as unsensitised. If the blood reacts with 50% of donors (50% of the panel or 50% calculated reaction frequency [cRF]), they are 50% sensitised, and if blood reacts with 100% of donors, they are highly sensitised. Unfortunately, some highly sensitised candidates wait many years for a compatible transplant, although the antibodies responsible for sensitisation can decrease with time.

United Kingdom matching system

Within the United Kingdom, each transplant centre has a local list of recipients awaiting transplant. There is a national database held at NHSBT in Bristol. Each deceased donor is tissue-typed at the local transplant centre and the details sent to NHSBT, where the closest tissue match is found from the central computer. The donor organ (s) are then sent to the recipient centre for transplant.

A new scheme for the national allocation of kidneys was adopted in the United Kingdom in 2019 (NHSBT 2022b). This replaced the previous scheme implemented in 2006. The new scheme replaced the previous five-tier system with a two-tier system. This new scheme covers the allocation of both DBD and DCD donor kidneys and the aim was to provide equity to those recipients more difficult to match. The aims of the new scheme were to better utilize deceased donor organs, improve donor-recipient matching, provide equity for difficult to match recipients, minimize long wait times and to achieve equivalent patient and graft survival. The main differences between the 2006 and 2019 allocation schemes are listed below.

Previous allocation policy in effect from 2006:

- Five tiers based on matching
- Paediatric patients (< 18 yrs) prioritised
- Points allocated according to various factors including waiting time and location
- Separate allocation scheme for DBD & DCD organs

New allocation scheme:

- Two-tier system, tier A (highly sensitized, or 7 years or more waiting time) tier B (all other patients based on a points allocation system)

- Tailored HLA match by age (better match for younger patients)
- Age is continuous to benefit young adults.
- Avoid prolonged waiting time (predicted by HLA type, sensitisation, blood group).
- Waiting time starts from dialysis start date or listing whichever is first.

Although predictive models indicate that this scheme will meet expectations, time is needed to confirm that this is the case (Watson et al. 2020). Unfortunately, the effect of the COVID-19 pandemic on organ donation and transplantation has affected the evaluation of the effect of this scheme.

DECEASED DONATION

The majority of kidney transplants currently performed in the United Kingdom are from deceased donors. Deceased donors fall into two categories: donation after brainstem death (DBD) or donation after circulatory death (DCD). DBD donors are patients whose death is confirmed using neurological criteria (also known as brainstem death or brain death), this is only possible in patients who are maintained on mechanical ventilation.

CAUSES OF BRAINSTEM DEATH

The most common causes of brainstem death are listed in Box 9.5. Cerebral swelling resultant from trauma or anoxia and intracerebral bleeding can cause raised intracranial pressure, which forces the cerebral hemispheres through the tentorial hiatus, thus compressing the brainstem and interrupting its blood supply. Such herniation of the cerebral tissue is usually described as *coning* and results in irreversible damage to the brainstem.

BRAINSTEM FUNCTIONS

The brainstem is responsible for the capacity to breathe spontaneously and the capacity for consciousness. If the brainstem is irreversibly damaged then there is loss of function and it is argued that 'death entails the irreversible loss of those essential characteristics which are necessary to the existence of a living human person'.

Brainstem death diagnosed by signs of irreversible damage to the brainstem is an accepted concept in most countries of the world.

BOX 9.5**COMMON CAUSES OF BRAINSTEM DEATH**

- Intracerebral bleed or infarction
- Head trauma
- Cerebral hypoxia due to:
 - Respiratory arrest
 - Cardiac arrest
 - Smoke inhalation/carbon monoxide poisoning
 - Cerebral tumour
 - Drug overdose
 - Intracranial infection

Certain conditions must be met before brainstem death testing can take place:

- The patient is deeply comatosed, unresponsive, and apnoeic with lungs artificially ventilated.
- A positive diagnosis or known condition has led to the diagnosis of irreversible brain damage.
- Potentially reversible causes of coma have been excluded.

Possible causes of coma that must be excluded are primary hypothermia (the patient's temperature must be greater than

34 °C for testing to take place), effect of depressant drugs, potentially reversible circulatory, metabolic and endocrine disturbances, and potential causes of apnoea. Testing will then take place to ascertain the absence of brainstem reflexes:

- The pupils are fixed and do not respond to sharp changes in light intensity.
- There is no corneal reflex.
- The oculovestibular reflexes are absent.
- There are no motor responses within the cranial nerve distribution in response to stimulation of any somatic area.
- There is no cough reflex response to bronchial stimulation by a suction catheter placed down the trachea to the carina, or gag response to stimulation of the posterior pharynx with a spatula.
- There is no evidence of spontaneous respiration or respiratory effort during the apnoea test (loss of capacity for spontaneous breathing).

Brainstem death diagnosis

Tests to diagnose brainstem death originated from the Harvard Medical School criteria (Harvard Medical School 1968) and were published in the United States in 1968. A UK Code of Practice for the diagnosis of brainstem death was agreed by the Academy of Medical Royal Colleges in 1976 and last updated in 2008 (Academy of Medical Royal Colleges 2008).

Declaration of brainstem death

The UK Code of Practice recommends that brainstem death testing should be carried out by two medical practitioners who have been registered for a minimum of 5 years and 'who have expertise in this field'. At least one should be a consultant. Testing should be performed by two doctors together and should be performed completely and successfully on two occasions. Neither doctor should be a member of the transplant team or associated with potential transplant recipients.

Time of death

The time of completion of the first set of tests is legally the time of death, and this should be recorded as such on the death certificate.

ABSOLUTE CONTRAINDICATIONS TO ORGAN DONATION

- Age > 85 years (on or after their 85th birthday)
- Primary intracerebral lymphoma
- All secondary intracerebral tumours
- Any active cancer with evidence of spread outside affected organ within three years of donation
- Melanoma (except completely excised Stage 1 cancers)
- Active (not in remission) haematological malignancy (myeloma, lymphoma, leukaemia)
- Definite, probable, or possible case of human transmissible spongiform encephalopathy (TSE), including Creutzfeldt-Jakob disease (CJD) and vCJD (variant Creutzfeldt-Jakob disease), individuals whose blood relatives have had familial CJD, and other neurodegenerative diseases associated with infectious agents
- TB: active and untreated or during the first 6 months of treatment
- West Nile virus (WNV) infection
- HIV disease (but not HIV infection)

- History of infection with Ebola virus
- Bacillus anthracis (anthrax)
- Dengue virus
- Proven coronavirus without recovery (Coronavirus infection includes Covid 19, SARS and MERS.)
- Rabies
- Yellow fever
- Viral haemorrhagic fevers – including Lassa, Ebola, Marburg, and CCHF viruses
- Chikungunya virus (Donation can be considered 6 months post-recovery)
- Progressive multifocal leukoencephalopathy (PML)
- Zika virus (Donation may be considered 6 months after recovery.)
- Systemic infection with candida/aspergillus/other fungi/endemic mycoses

ORGAN-SPECIFIC CONTRAINDICATIONS FOR POTENTIAL KIDNEY DONORS

- Chronic kidney disease (CKD stage 3B or worse, eGFR<45).
- Long-term dialysis (not related to acute illness).
- Renal malignancy: Prior kidney tumours of low grade and previously excised would not necessarily exclude donation.
- Previous kidney transplant (>6 months previously).

(NHSBT 2022c)

The following conditions may preclude donation, but individual donors should be discussed with the specialist nurse for organ donation (SNOD) as they may still be suitable:

- Bacterial meningitis
- Viral meningo-encephalitis
- Influenza
- Bacteraemia
- Abscesses
- MRSA (or other drug resistant bacteria)
- Malaria
- Fungal infection

- Lyme disease
- Chagas disease (*Trypanosoma cruzi*), apparent in some Latin American migrants

(SaBTO 2020)

It is recommended that critical care staff consider organ donation in all those with brainstem death and refer to the SNOD for a decision regarding medical suitability. General Medical Council (GMC) and NICE guidance both recommend that consideration for organ donation should be a routine part of end-of-life care, and the wishes of the individual patient with regard to donation should be fulfilled wherever possible (GMC 2022; NICE 2016).

In order to keep transplants safe, Department of Health guidelines state that ‘certain medical and social information’ must be given. The SNOD undertakes a three-step assessment process of the donor:

1. Clinical risk assessment. This includes interviews with the donor family/next of kin to obtain information relevant to donation (Box 9.6).
2. Prior to donation, the donor undergoes a physical examination.
3. Microbial testing is conducted to detect potential transmissible infection (SaBTO 2020).

REQUESTING DONATION

In the United Kingdom, the legal requirements for organ donation are laid down in the Human Tissue Act (2004). This act established the Human Tissue Authority (HTA) as the regulatory body for all matters concerning the removal, storage, use, and disposal of human tissues (except gametes and embryos) for scheduled purposes and includes responsibility for living donor transplantation. The HTA’s code of practice on consent sets out guidance on how the law should be applied, encompassing issues of consent.

In England (along with Wales and Jersey), deemed consent legislation has been implemented. This means that if a patient is not in one of the excluded groups and has not confirmed a decision not to be an organ donor, then it is considered that the patient agrees to donate their organs.

Religious beliefs

As far as it is known, no major religious groups in the United Kingdom object to the principles of organ donation and transplantation. Some groups feel that it is only permissible if donors themselves had requested donation. These groups include orthodox Jews, Christian Scientists, and some Hindu groups. Jehovah’s Witnesses have religious

BOX 9.6**KEEPING TRANSPLANTS SAFE: DONOR DATA COLLECTED BY THE SNOD ON THE DONOR ASSESSMENT FORM**

- Treatment received for the illness prior to donation (including antimicrobial and other drug therapy, doses, and duration of treatment)
- Vaccination history and immunisation status
- History of receipt of blood, blood components, blood products, tissue, or organ graft
- Previous or current immunosuppression by disease or drugs
- Travel history
- History of contact with animals or other vectors (risk of transmission of zoonotic infection)

- History that may have put the donor at increased risk of transmissible spongiform encephalopathies (TSEs)
- History of malignancy, infectious disease, or exposure to infectious disease
- Behavioural history that could have put the donor at risk of transmissible pathogens

This will include questions about risky behaviours such as recreational drug use, men who have sex with men (MSM), sex with commercial sex workers or sex with a partner known to have a sexually transmissible disease, acupuncture, tattooing, and body piercing.

objections to blood transfusions but feel that donating or receiving organs is a matter for all Jehovah's Witnesses to decide for themselves.

It is often thought that the Muslim faith does not support donation and anecdotal evidence suggests that British Muslims are, in general, reluctant to donate organs. However, recent legislation has approved donation and transplantation in Muslim countries such as Saudi Arabia (Ghaly 2012). Fatwas issued by the Muslim Law Council have stated that Muslims may donate organs, they may carry donor cards, and their next of kin may give permission for donating (NHS Blood and Transplant (2024)). Previous reluctance to donate may have been cultural rather than religious; therefore, information and liaison with Muslims will be vital in order to encourage donation.

Byrne et al. (2017) states that there is an increased prevalence of ESKD in those from ethnic minorities in the UK. Major causes are the higher incidence of hypertension and diabetes combined with other reasons that are, as yet, unknown. Although none of the major religions forbids organ donation, there are fewer deceased organ donations from this community. The reasons for this are complex but include mistrust of the NHS, lack of available culturally sensitive information, and lack of engagement with the community in general (Department of Health 2010). Language and cultural barriers seem to have inhibited the uptake of public health messages pertinent to organ donation and transplantation.

Strategies to increase the number of donors in the UK recognise the need to engage with Black and minority ethnic groups in order to address the shortage of donor organs from this group (NHSBT 2017).

Other issues may also be adversely affecting the deceased donation rate from within *all* groups, particularly aspects relating to gaining consent from the bereaved.

Fear of increasing the distress of the family

Critical care staff have expressed fears that offering donation may increase the distress of the bereaved; however, experience suggests that offering the choice to donate, if performed with empathy, does not increase distress (Marck et al. 2016). Indeed, donor families report that the act of donation brings comfort and something positive in an otherwise negative situation. Family members were consoled by the fact that by consenting to donation, they had allowed their relative to help others. In the presence of a diagnosis of brainstem death there can be no hope for the patient, but donation can be an option offering hope of life for others.

Acceptance that death has occurred

It is crucial that the bereaved family have accepted the fact that death has occurred before donation is requested. In the case of brainstem death, the acceptance of death is more difficult for the family as they are asked to accept a 'new concept of death'. The accepted concept and image of death involves a cold, lifeless body without a heartbeat; however, in the case of brainstem death the family are presented with an image of a warm patient with a heartbeat who appears (due to the ventilator) to be breathing. Therefore, the visual message is one of life but the verbal message is one of death. In such cases, denial is often enhanced and relatives must struggle to understand and accept the

situation. Denial may be particularly acute in the case of an intracerebral bleed where there is no outward sign of injury or trauma.

Clear communications must ensue; the core message should be that there is no hope of recovery. Irreparable damage has occurred and, in the case of brainstem death, the brain has died – death of the brainstem is death of the person.

When to offer donation

Several factors when approaching families of potential donors, these include ensuring involvement of the multi-disciplinary team, ensuring staff have the appropriate skills to discuss donation and ensuring that donation discussion take place separately from discussion around withdrawal of treatment. It is important that acceptance that death is inevitable has occurred prior to the approach being made regarding organ donation (NICE 2016).

Who should offer donation?

There is evidence that the SNOD is the best person to make the initial approach to the family to discuss donation (Hulme et al. 2016). The skill of the person making the approach to the family and the timing of the approach are important considerations that can positively influence consent rates.

How to offer donation

There are no ‘right’ words; each situation is unique, and families will have their own individual responses. The SNOD making the approach to the family will be aware of whether the patient was on the organ donor register or not and will use the framework of deemed consent to inform the discussion. Many relatives will have additional questions concerning the process of donation and its implications at this time. The family may require reassurance on the following issues:

- The donor will feel no pain.
- There will be dignity and respect throughout the donor surgery.
- The body will not be grossly mutilated or disfigured.
- The surgical wound will be sutured.
- They can view the body after surgery and the funeral will not be delayed.

The SNOD works closely with other healthcare professionals to answer further questions and to facilitate the wishes of the family. It can be reassuring to the family that he or she will be present throughout the surgery and at the end to oversee and continue care. They will also ensure

that the bereaved can see the deceased after surgery in the chapel of rest if this is their wish.

Unconditional gift

It is important to stress that organ donation is a voluntary ‘unconditional gift’. One case, much publicised, reported that the bereaved had stated that the organs ‘must only be given to white recipients’ (Guardian 1999). Such a condition is totally unacceptable and there is now legislation that prohibits the placing of any conditions when agreeing to organ donations (HTA 2023).

Continuing family support after donation

Letters of thanks containing brief, anonymous information concerning the transplant recipients are given or sent to the donor family after the donation. Further help and support are also offered. Many families state that the news of the successful transplants is a source of comfort. More recently, transplant coordinators have arranged meetings between donor families and recipients. Such meetings have been requested by both parties and have followed careful counselling and preparation to ensure the willingness of all individuals involved.

REFUSAL TO DONATE

As part of measures to improve organ donation rates in the United Kingdom, an audit of potential donors in all UK intensive care units and emergency departments commenced in 2003 and has continued until the present. The aim of the audit is to determine the number of potential organ donors. Results from the report for 2021/2022 indicate that 98.7% of patients who met the criteria for DBD were referred as potential donors, and 90.4% of patients meeting the criteria for DCD were referred. Of the families approached regarding potential organ donation, the report cites the following as the main reasons for refusal of consent:

- Patient stated in the past they did not wish to be a donor (DCD 27.3%, DBD 33.1%).
- Family felt it was against their religious/cultural beliefs (DBD 10.3%, DCD 4.4%).
- Family members were not sure the patient would have agreed to donation (DBD 9.3%, DCD 11.8%).
- Family did not want surgery to the body (DBD 9.3%, DCD 8.5%).

Further analysis of the results of the audit show that the age but not gender of the potential donor has some impact on the refusal rate (families of older patients were more likely to consent). Relatives of ethnic minority groups

are more likely to deny consent than those of White potential donors (NHSBT 2022d).

Despite improvements in consent rates, there is still some lost potential. Therefore, it is vital that information programmes to allay fears and to present the successes of transplantation continue. It is also helpful to implement education for healthcare staff to examine the issue of requesting donation so that personnel will feel comfortable when offering this option of hope to the family.

Transplant coordinator groups have introduced workshops on breaking bad news and the approach for donation for nursing and medical colleagues working in intensive care and emergency departments. Such workshops use informed actors and provide a forum and a safe environment for staff to examine sudden traumatic death, the reactions of relatives, and responses that will facilitate the approach for donation.

If the family agrees to donation, the ventilation continues and preparations for the donor surgery are made, but if the family refuse donation, then ventilation will cease.

It is always helpful for the family if the deceased had indicated intent on the National Register or had discussed the issue with them. Most families want to fulfil the wishes of their loved one, and if they know the thoughts of the deceased with regard to donation, then the question and decision can be made easier.

CLINICAL CARE OF A POTENTIAL ORGAN DONOR

Brainstem death results in changes to normal homeostatic mechanisms; such changes will ultimately result in cardiac arrest. Once permission has been given for donation, it is important to stabilise the condition of the donor to ensure optimal condition of the organs for transplantation. NHSBT provide guidance for critical care staff regarding the care required to optimise the donor prior to donation (NHSBT 2022e).

ROLE OF THE SPECIALIST NURSE FOR ORGAN DONATION

All kidney transplant centres depend on local SNODs. They are senior practitioners who offer a 24-hour service to intensive care units with regard to organ donation. The specialist nurse's responsibilities are to:

- determine suitability of the potential donor;
- determine which organs/tissues can be donated;
- identify any risk factors for transmission of disease from potential donor to potential recipient.

ORGANISATION OF THE ORGAN DONATION PROCEDURE AND SURGERY

The specialist nurse will be available to advise and support the donor family and critical care staff throughout the donation process. Organisation of the organ donation is complex, and it is the specialist nurse's role to ensure the arrangements for donation are made with a minimum of distress to the donor family and the critical care staff. The majority of organ donations today are multiple donations, and it is the specialist nurse who organises the necessary clinical tests, liaises with the various recipient teams, and arranges the donor surgery (Box 9.7).

BOX 9.7

ORGAN DONATION: ROLE OF THE SNOD

- Completely and clearly document a comprehensive assessment of the donor, including medical, behavioural, and travel history.
- Communicate this information to the recipient transplant centres.
- Key components of donor assessment:
 - Gather information from health care team involved in current and past medical care including the patients GP and allied health professionals.
 - Review results of clinical investigations, including review of medical and nursing notes.
 - Conduct structured discussion with patient's next-of-kin/family.
 - Conduct a full and detailed physical examination.
 - Seek further specialist advice where necessary.
- Organise any further clinical tests and blood tests.
- Liaise with NHSBT duty office.
- Liaise with recipient teams.
- Liaise with theatre staff and obtain theatre time:
 - Accompany donor to theatre.
 - Assist surgical teams.
 - Support theatre personnel.
- Provide final care of donor.
- Contact with donor family offering information and/or support.
- Provide information and thanks to donor hospital personnel.

PERMISSION FROM THE CORONER

If the case comes under the jurisdiction of the Coroner (or Procurator Fiscal in Scotland), then permission must be obtained to proceed to organ donation. Cases that require Coroner or Procurator Fiscal permission include:

- road traffic accident;
- suspicious deaths/suicide;
- deaths less than 12 hours after surgery;
- traumatic deaths.

Permission will be granted if the donation will not interfere with the Coroner/ Procurator Fiscal's legal responsibility to establish the cause of death. In some cases, a Home Office pathologist will be present at the retrieval to document the procedure as part of the investigation into cause of death.

REMOVAL OF KIDNEYS FROM A MULTIORGAN DONOR

It is most common now for kidneys to be taken out as part of an operation from a multiorgan donor. This requires careful coordination between the liver, kidney, and thoracic teams involved to make sure that there is no compromise to viability in any of the transplanted organs.

The exact details of the operation vary from centre to centre, but the principles include a generous incision giving good exposure to the organs of interest with the heart still beating, and placement of cannulae for in situ perfusion and cooling:

- A bilateral subcostal incision with a midline sternotomy is a common approach to the chest. The heart and lungs are inspected and mobilised first to allow rapid removal at a later stage.
- A careful laparotomy is carried out before dissection of the major blood supply to the liver. The common bile duct is transected, and the gall bladder is incised and flushed to prevent biliary autolysis.
- Cannulae are placed into the aorta and portal vein via the mesenteric vein for perfusion. The distal inferior vena cava is cannulated and used for vascular drainage.
- Ventilation ceases when the aorta is cross-clamped. Perfusion starts simultaneously to minimise warm ischaemia.
- The organs are removed; first, heart and lungs, followed by the liver, and then the kidneys. Careful cooperation

between teams is required to minimise damage to the various organs. The pancreas is used for transplantation with increasing success; concurrent retrieval with the above organs has not been associated with adverse outcome.

- Before closure of the abdominal incisions, specimens of donor lymph nodes and spleen are removed for histocompatibility and tissue typing.

SURGICAL TECHNIQUE FOR DECEASED DONOR NEPHRECTOMY

If the kidneys are to be removed alone, bilateral nephrectomy is accomplished through a long midline incision or a bilateral subcostal incision. The kidneys are either taken out *en bloc* or individually on patches of inferior vena cava and aorta. The technique preferred in this centre entails the removal of an individual kidney on a patch of aorta and inferior vena cava. The technique is as follows:

- Abdominal incision and laparotomy are performed as for multiorgan retrieval.
- The aorta is dissected up to the superior mesenteric artery and the inferior vena cava dissected above the renal veins.
- Slings are placed around the aorta and the inferior vena cava above the bifurcation ready for tying at a later stage.
- A catheter is passed into the aorta through an incision just above the bifurcation. The balloon of the catheter is distended with fluid and ties placed around the aorta distal to the balloon to hold it in place. Care must be taken not to overdistend catheter balloons, as this can obstruct the lumen of the catheter.
- A similar procedure is carried out with the inferior vena cava just above the confluence of the right and left common iliac veins, and the aorta and inferior vena cava below the catheters are tied off.
- The aorta is tied off in the upper abdomen and perfusion is started through the Foley catheter (Figure 9.3). As perfusion starts, ventilation is discontinued.
- The kidneys begin to get cold at this stage and, whilst the perfusion fluid is running through into the kidneys and out through the renal veins, the kidneys should be surrounded by ice to assist cooling and prevent rewarming from the adjacent tissues.
- The inferior vena cava above the renal veins is ligated and the blood from the kidneys drains out through the catheter in the inferior vena cava.

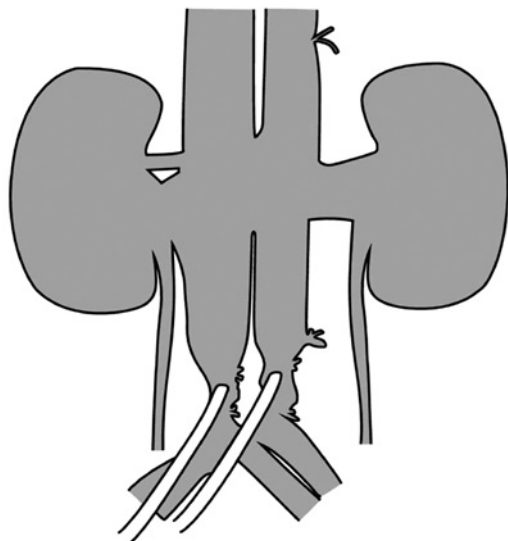


FIGURE 9.3 Perfusion catheters in situ for deceased donor nephrectomy.

- After 2 l of perfusion fluid has flushed through the kidneys and the kidneys are cold, they can be mobilised and the cannulae removed.
- The inferior vena cava is split up the middle and along the back, taking care not to divide the right renal artery. The aorta is also divided anteriorly and posteriorly, taking care to avoid damaging the left renal vein, which crosses in front of the aorta. Having done this, each kidney is taken out with a section of aorta, inferior vena cava, and long length of ureter and placed in iced saline, where it is reflushed with preservation fluid.
- Normally, no further dissection is done at this stage, but the kidney is placed in sterile bags and sent at 4 °C to the receiving centre. Further dissection of the kidney is performed immediately before subsequent transplantation into the recipient.

Following removal, each kidney is examined for any surgical injury and unusual anatomy and is placed in a sterile bag with a small amount of perfusion fluid. This bag is then placed inside two further polythene bags to ensure sterility. The kidney is finally packed into a transport container with ice.

ORGAN PRESERVATION

The aim of preservation is to maintain the organ in an optimal condition until transplantation can occur. All living cells require oxygen to survive. Once the blood supply to

the organ ceases, the lack of oxygen will result in cellular ischaemia. Cooling the organ will reduce the cellular metabolism and thus help to minimise subsequent damage. Ischaemia that occurs before the organ is cooled is termed warm ischaemia.

Warm ischaemia

If the blood supply to the kidneys is interrupted without cooling, the tubular cells suffer warm ischaemia, resulting in acute tubular necrosis (ATN). ATN may be reversible if the warm ischaemia time is limited (approximately 45 minutes). However, should the warm ischaemia extend longer than an hour, the glomeruli are likely to suffer irreversible damage and the kidney may not regain function. During DBD donation, the ventilation and blood supply continue until the perfusion system is in place. As perfusion with cooled fluid commences, the ventilation ceases. Thus, the kidney is immediately cooled and the warm ischaemia is limited to approximately one to two minutes only.

Cold ischaemia

The ice should maintain the kidney at approximately 4 °C, thus minimising ischaemic damage and enabling transport to the transplant centre. The time from the beginning of cooling to reperfusion and rewarming at the time of transplantation is termed the *cold ischaemia* time. Most kidneys can be stored for over 24 hours if necessary. However, evidence suggests that prolonged cold ischaemia has an impact on post-transplant outcomes, with a 4% increased risk of graft failure for every hour after 21 hours of cold ischaemia (Johnson et al. 2010).

DONATION AFTER CIRCULATORY DEATH

Donation after circulatory death was previously known as non-heartbeating donation or donation after cardiac death (also abbreviated to DCD). This refers to organs retrieved for transplantation from a donor whose death is confirmed using cardiorespiratory criteria as opposed to neurological criteria. Prior to the introduction of brainstem death criteria in 1976, all organ donations came from donors who had suffered circulatory death; the introduction of this criteria and the ability to maintain potential donors on artificial ventilation led to the reduction in this practice. However, the lack of suitable organ donors in the intervening years has led to the increasing use of DCD donors. There are two categories of DCD donation: ‘controlled’ where there is planned withdrawal of life-sustaining treatment, or ‘uncontrolled’ where the donor suffers an unexpected cardiac arrest and resuscitation is not attempted.

Relative and absolute contraindications for DCD donation are the same as for DBD donation. To establish death, the clinician must observe the patient for at least 5 minutes to ensure that irreversible cardiorespiratory arrest has occurred. Following this, a double balloon triple lumen catheter is inserted into the femoral artery, the catheter is guided into the aorta, and the top balloon inflated to occlude the aorta. The lower balloon is then inflated and cold perfusion fluid is flushed through the catheter and into the kidneys. A further catheter is inserted into the femoral vein to allow the perfusion fluid to drain. This procedure allows the organs to be perfused with cold solution prior to removal, allowing time for the patient to be moved to the operating theatre whilst minimising warm ischaemic time.

DCD donation programmes vary worldwide. In the UK, DCD donors make a significant overall contribution to deceased donation, representing 44% of all deceased organ donors in 2021–2022 (NHSBT 2022a). All DCD programmes in the UK at the present time are controlled, with no uncontrolled donation programmes currently active.

The time interval between treatment withdrawal and cold perfusion in the donor, known as warm ischaemia, can make DCD donors unsuitable to donate some solid organs such as liver and pancreas. Although this extended warm ischaemic time can affect short-term outcomes in kidney transplantation and lead to an increased incidence of delayed graft function, longer-term outcomes are improving.

There are ethical and legal questions to consider with the practice of DCD donation – for example, to what extent should clinical interventions be undertaken in the dying patient in order to facilitate organ donation, such as admission to intensive care, arterial and venous catheterization, and inotropic support? In order to clarify the legal and ethical issues surrounding DCD donation, the UK Donation Ethics Committee and the Academy of Medical Royal Colleges set out recommendations for practice related to DCD donation for those caring for dying patients. The guidance is based on two principles: firstly, that where donation is a possibility, full consideration should be given to this when caring for a dying patient; and, secondly, that donation is an integral part of a patient's end of life care if it is established that donation would be consistent with their wishes, values, and beliefs (UKDEC 2011).

The time between referral for donation and actual donation can be distressing for the family and friends of the patient, and there is evidence that the time taken from decision to donate and actual donation can lead to some

families refusing consent for donation (NHSBT 2022f). The SNOD will assume the same role as in DBD donation and will provide support and assistance to both the donor's family and to the team providing care to the patient.

LIVING DONATION

In the early days of transplantation, live related transplants were the only possible option but, with the advent of deceased donation and improved immunosuppression regimes, most centres have primarily concentrated on deceased donation. The reduced use and focus on live donor transplants was due, in part, to the fact that some clinicians struggled with the ethical issue of subjecting a healthy and fit person to the risks of major surgery that had no personal benefit for them, albeit there would be benefit to their family member.

ETHICAL ISSUES

The core factors of the living donation debate involve the critical issue of a balance between 'doing good without doing harm' and the concept of altruism.

PHYSICAL WELL-BEING – DOING GOOD WITHOUT DOING HARM

The donation will most certainly 'do good' in benefiting the recipient but may also 'do harm' to the donor, as the surgical procedure exposes the living donor to major clinical risks. Mortality from living donor surgery is low; however, donor deaths have been reported. Early post-operative complications may occur, including chest infection, deep vein thrombosis, wound infection, and post-surgical depression, amongst others. The lifetime risk of ESRD after kidney donation is low, occurring in less than 1 : 200 donors (0.5%) (BTS 2018). BTS guidelines (2018) recommend that counselling and consent of potential living kidney donors include acknowledgement that the baseline risk of ESRD is increased by donation. Discussion with potential donors must be informed by those factors known to increase ESRD risk post-donation, including donor age, sex, race, BMI, and a family history of kidney disease (BTS 2018).

PSYCHOLOGICAL WELL-BEING – DOING GOOD WITHOUT DOING HARM

Undoubtedly, many living donors gain psychologically from the act of giving. Early studies suggest that donors describe the act 'as one of the most meaningful experiences

in their lives' (Fellner and Marshall 1968). The satisfaction of helping a 'loved one' return to a normal lifestyle is very rewarding for many. Long-term follow-up of donors has demonstrated no adverse effects on psychological health or social status (Fournier et al. 2012).

ALTRUISM

Altruism – the act of unselfishness – means giving freely without thought of reward. Much debate has surrounded this concept, with writers in the 1960s and 1970s questioning the fundamental reasons for giving. Kempth (1966) reported that although donors were 'consciously altruistic' there was 'considerable unconscious resentment' towards the recipient and towards hospital personnel who requested or encouraged the donation. Other studies suggested the presence of a degree of coercion or subtle familial pressure. There were also reports of financial incentives or other 'material rewards' offered by recipients to donors to encourage donation. Although many of these early studies involved small numbers of donors and recipients, the negative findings led many centres to pursue deceased donor options.

Later studies in the 1970s and the 1980s reported more positive psychological findings (Smith et al. 1986), and this led to the development of more extensive live donor transplant programmes in many UK centres.

More recent studies found that not only was there a low risk of psychological issues such as depression, anxiety, and regret amongst kidney donors but was lower than the comparable nondonor population (Holster et al. 2018; Krishnan et al. 2020).

Despite this, studies have identified factors that are linked to an increased risk of donors experiencing psychological issues. These include younger age, lack of social support, unemployment, and history of psychological problems (Timmerman et al. 2016). This highlights the need for careful assessment of donors and ongoing support pre- and post-donation to mitigate these risks.

BENEFITS FOR THE TRANSPLANT RECIPIENT

Although the ethical issues have been recognised and much debated, the decision to continue with living donation has usually been based on the very real benefits that ensue for the recipient. Living donation has always demonstrated higher graft survival rates than deceased donation, regardless of genetic relationship or tissue matching. Although recent advances in immunosuppression

have narrowed the gap between the two groups, in most cases the living donor grafts still have a better survival rate at one year and a significantly higher probability of function in the long term. The recipient benefits from a reduction in the time on dialysis, which is recognised as contributing to an improved outcome following transplantation.

The living donation can be planned to take place at the most suitable time (medically and socially) for the recipient and donor. As kidney function deteriorates, transplantation can be planned for the pre-dialysis phase (pre-emptive transplantation), thus avoiding the physical and psychological stress of dialysis adjustments. Studies have shown an improved outcome for recipients transplanted pre-emptively. Such benefits have encouraged the expansion of living donor programmes.

TRANSPLANT RATES

Living donor programmes vary widely throughout the world, but several European countries have substantial live donor programmes (ERA 2020). The United Kingdom had a low rate, with only 5% of the total transplant programme resulting from living donation in 1981, but it was 28% in 2021–2022 (Figure 9.4).

LIVING UNRELATED DONATION (GENETICALLY UNRELATED – EMOTIONALLY RELATED)

In Norway in the early 1990s, parents, siblings, adult children, uncles, aunts, grandparents, and spouses were accepted as donors. Spouses are, of course, genetically unrelated but were recognised as 'emotionally related'. The Norwegian experience showed that transplantation between spouses (partners) could achieve graft survival rates equal to the best achieved with deceased donor organs. Similar results for transplantation between partners were reported in the United States (Terasaki et al. 1997). Centres across the world are now utilising spousal/partner donors and also other donors who have a demonstrable relationship with the recipient, such as close friends. However, all centres stress that the donor must be well motivated and well informed before proceeding.

BUYING AND SELLING OF ORGANS

Living donor transplantation in the United Kingdom is controlled by strict laws to prevent the possibility of illegal practices such as financial payments and coercion. In

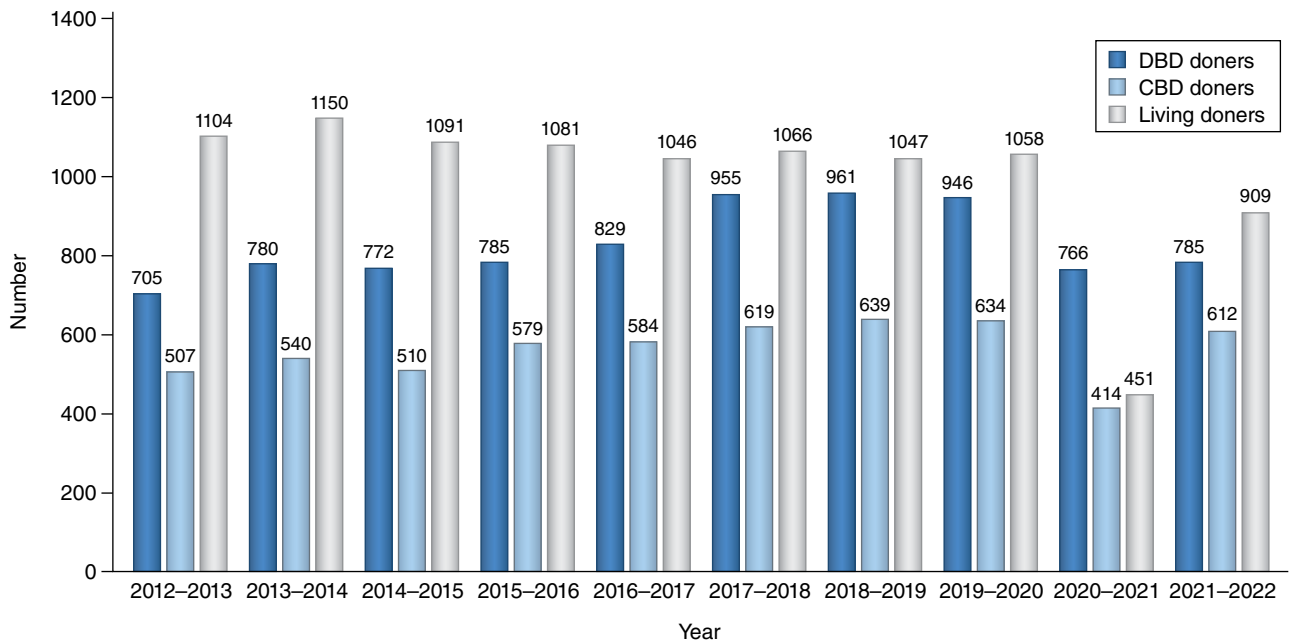


FIGURE 9.4 Number of deceased and living donors in UK, 1 April 2007–31 March 2022. Source: from *Annual Report on Kidney Transplantation 2021/22*, NHS Blood and Transplant.

the United Kingdom, the Human Tissue Act 2004 came into place in 2006, which placed the principle of consent at the centre of living donation, and indeed to all issues relating to donation and the taking of, storage, and use of human tissues and organs. It covers England, Wales, and Northern Ireland, with the Human Tissue (Scotland) Act 2006 covering Scotland. The HTA, established in 2005, implemented the provisions of the Act and the EU Tissue and Cells Directive, which also came into force in 2006. Under the Act, the approval process is the same for directed genetically or emotionally related organ donation. Local independent assessors (LIAs), trained and accredited by the HTA, assess all donor/ recipient pairs, and where the requirements are met, give approval to proceed. Prior to 2006, legislation precluded the use of altruistic donors who wish to give anonymously to the donor pool; however, it is now possible for nondirected altruistic donation to take place, with the donor kidney being utilised in the same way as a deceased donor kidney. The new Act has also allowed the development of the National Living Donor Kidney Sharing Scheme (NLDKSS).

The buying and selling of organs does occur in some of the developing countries and is an accepted practice. Indeed, some clinicians have suggested that a similar system, strictly controlled by legislation, could be introduced in the UK to increase transplant rates. The ethical

and moral ramifications would be immense, and at present such a concept is illegal and totally unacceptable to most.

NATIONAL LIVING DONOR KIDNEY SHARING SCHEME

The NLDKSS in the UK was introduced to allow donor and recipient pairs who were incompatible for transplantation to be matched with other donors and recipients in the same situation and the donors to be effectively 'swapped'. This procedure can be carried out between more than two pairs, known as *pooled donation*. This scheme is administered by NHSBT and individual units are responsible for donor and recipient work-up prior to registering for the scheme. Matching runs are carried out on a 3-month basis and the units involved are informed of any matches thereafter. Once units are informed of a match, a cross-match blood test is arranged between relevant donors and recipients. Once results of the cross-match confirm that the transplant can proceed, the donor and recipient are interviewed by their local IA and a report is submitted to the HTA. The transplant cannot proceed until HTA approval is confirmed. The transplant operations take place simultaneously at each centre, with kidneys travelling from the donating unit to the receiving unit. Anonymity between donor and recipient is maintained in the same way as for deceased donation.

THE FUTURE FOR LIVING KIDNEY DONATION

The Living Donor Kidney Transplant 2020 strategy was launched in 2014 and achieved its aim of increasing rates of living donation in the UK (NHSBT 2014). A further strategy to build on this achievement was launched in 2021. Organ Donation and Transplantation 2030: Meeting the Need sets out a 10-year vision for donation and transplantation in the UK (NHSBT 2021). This strategy encompasses deceased and living donation and aims to increase donation and transplantation rates, develop a sustainable service, and ensure equity of access to transplantation for those from disadvantaged groups.

DONOR AND RECIPIENT MATCHING

Individual tissue type is inherited as half from each parent. Therefore, matching within a nuclear family unit will usually result in a potential donor who is HLA-identical, a one-haplotype match, or a mismatch.

IMMUNOLOGICAL ASPECTS

Matching for the major histocompatibility complex (MHC) will take place. Figure 9.5 demonstrates tissue-type inheritance using the donor-related (DR) locus. Therefore, potential donors may be:

- HLA-identical, as with DR1:3 (siblings);
- a one-haplotype match, as with DR1:3 and DR1:8 (siblings);
- DR1:4 and DR1:3 (parent–child);
- unmatched, as with DR1:3 and DR4:8 (siblings).

The long-term graft survival rates are better with better matching, but a mismatched living donor kidney

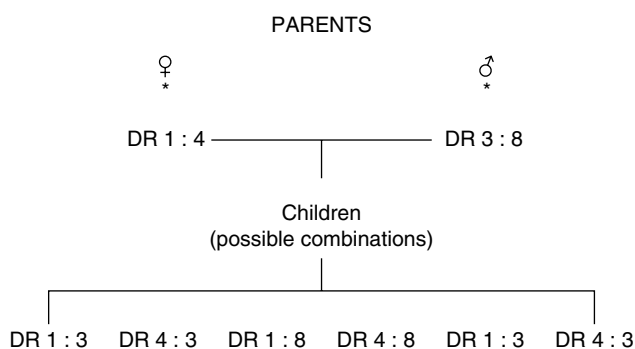


FIGURE 9.5 An example of tissue-type inheritance.

transplant gives better results overall than well-matched deceased donor transplants.

Psychological issues

The question of the possibility of living related donation may bring unity to a family group, but it may also bring conflict. Being deemed unsuitable to donate can lead to feelings of loss, disappointment, and guilt, and may undermine relationships with family members. Potential donors may not be prepared for this eventuality and the resulting emotional burden (Ralph et al. 2019).

Ongoing psychological support is a necessary part of a living donor programme. Donor and recipient must be well informed concerning the risks and benefits and also the psychological difficulties that may develop. Separate meetings, both for the donor and the recipient, with medical staff and nurse/counsellor should be planned so that feelings, fears, and anxieties can be discussed with honesty. The motivation to donate should be explored and, if appropriate, the donor should be offered the opportunity to withdraw without guilt or family conflict.

Similarly, the decision to receive should be explored and the recipient offered the opportunity to refuse. Some patients have refused living donation, preferring to wait for cadaveric grafts so as not to 'inflict my disease on my family'. The dynamics of the donor and recipient relationship must be well understood so that help and advice may be offered if difficulties arise.

ASSESSMENT AND PREPARATION OF DONORS

The living donor must be:

- well-motivated;
- in excellent health with two normal kidneys and normal kidney function;
- ideally compatible for blood group and cross-match with the recipient, although incompatible donors may proceed to donate via the kidney sharing scheme (LDKSS) or via ABOi programmes.

The assessment and preparation for living donation are extensive and normally carried out in stages over several weeks or months. Different centres will conduct tests at different stages, but most units complete the same catalogue of tests in order to ensure that the criteria are fulfilled. The British Transplant Society and UK Kidney Association has produced guidelines on this. It is recommended that the potential recipient should be evaluated for suitability for transplantation as early as

possible, to avoid any unnecessary delay. Donor assessment should be organised in a way that is acceptable to the potential donor, avoiding the need for repeated visits and inconvenience to home and work life as far as possible. Grouping tests and investigations together can minimise extra visits to hospital and an organised and focused approach to the process is good practice (see Boxes 9.8 and 9.9). This is best organised and monitored by the living donor coordinator who becomes the point of contact for potential donors and liaises between the various members of the multidisciplinary team (MDT). A donor health questionnaire has been developed by the BTS (2018, pp. 56–57) and this should be used for initial discussion and assessment with the donor.

Throughout the assessment programme, the donor is assured that it is possible to retract the offer to donate at any time. Such a decision will be strictly confidential; support and advice will be available. If the donor wishes, a medical reason not to donate can be provided. This medical reason is seen within the context of a ‘benevolent decision’ to enable the donor to retract without family conflict or distress, thus promoting full altruism.

PRE-OPERATIVE CARE FOR THE DONOR

Two separate surgical teams are usually involved with a living related donation. The donor team assumes responsibility for donor care and the transplant team takes responsibility for recipient care. The donor and recipient

BOX 9.8

INITIAL DONOR ASSESSMENT

- Donor previous medical history
- Blood group
- Tissue typing
- Urinalysis (urine microscopy, culture, and sensitivity, albumin/protein:creatinine ratio)
- Blood pressure, pulse, weight, and height

The aim is to identify unsuitable donors early in the process. If there are no contraindications at this point, the donor will move on to the next stage of assessment.

BOX 9.9

MEDICAL ASSESSMENT AND FURTHER INVESTIGATIONS

See British Transplantation Society guidelines (2018) for detailed information on donor assessment.

- Conduct full medical history and physical examination.
- Get history in relation to transmissible infection.
- Repeat urea, electrolytes, creatinine.
- Conduct liver function tests, fasting glucose, bone profile.
- Check blood count, and screen for coagulation issues.
- Screen for viruses
- Repeat urinalysis (urine microscopy, culture, and sensitivity, albumin/protein:creatinine ratio).
- Measure the glomerular filtration rate (GFR).

Clinical tests

- Chest X-ray
- ECG
- Imaging of kidneys to determine renal anatomy

Initially, imaging can be done by ultrasound (less invasive) and progress to preferred method of assessment of vessels. These tests include catheter angiography, digital subtraction angiography (DSA), computed tomography (CT), or magnetic resonance angiography (MRA).

Other tests can be performed as indicated, depending on family history and/or results of physical examination – for example, glucose tolerance test, thyroid function, echocardiogram. The donor assessment procedure aims to ensure the suitability of the donor, to minimise the risks of donation, and to ensure suitability of the donor kidney for the recipient. Donor confidentiality should be maintained at all times.

Donor assessment is generally carried out by medical and surgical teams that are not also caring for the recipient; this ensures separation of interest. The donor assessment process should be designed in such a way that straightforward noninvasive tests are carried out first; therefore, if donors are later found to be unsuitable, they can avoid more invasive testing.

BOX 9.10**DONOR PRE-OPERATIVE ASSESSMENT INVESTIGATIONS**

- ECG
- Chest X-ray
- DVT prevention and prophylaxis (NICE 2019)

Blood tests

- Final cross-match
- MRSA screening swabs (throat, nose, axilla, groin)
- Urinalysis, urine for microscopy, culture, and sensitivity
- Biochemistry
- Liver function tests
- Haematology and clotting screen
- Baseline measurement of blood pressure, pulse, respiration rate, temperature, and weight and nursing admission procedure

are usually both nursed within the transplant centre in separate rooms. However, they may be nursed together if they so wish, if there are language or other difficulties.

The donor and recipient are usually admitted on the day before transplant, and at this stage a further medical history and physical examination will be performed, along with an anaesthetic and physiotherapist assessment (see Box 9.10).

The immediate pre-operative care for the living donor will be similar to that given to patients undergoing conventional nephrectomy. However, particular attention is paid to informed consent, pre-operative hygienic care, and premedication.

SURGICAL TECHNIQUE OF NEPHRECTOMY

Living donor nephrectomy is always emotionally taxing surgery and can be technically difficult. Thus, whilst very rare, the risks are certainly not negligible, and major morbidity or death is very traumatic not only for the relatives but for the members of the surgical team themselves. The risk of death associated with living donor nephrectomy and the risks of short- and long-term complications must be fully explained. The clinician responsible for the living donor is required to 'give the HTA explicit assurance that the person intending to donate understands both the

generic and specific material risks of donation. This includes information about generic risks to which any reasonable person or all donors would attach significance, as well as information about individual risks to which the person consenting to donation is likely to attach significance' (BTS 2018, p. 38).

The traditional approaches for removing a kidney from a live donor are either transabdominal, intraperitoneal, or via the loin over the 11th or 12th rib, either spreading or removing the 11th or 12th rib. The intra-abdominal approach is usually through a transverse incision in the right or left upper quadrant. Laparoscopic nephrectomy, either hand assisted or totally laparoscopic, is the most common surgical technique used in the United Kingdom and may be transperitoneal or retroperitoneal in approach. The technique requires a high degree of surgeon training. The donor is placed in the flank position and the abdomen insufflated with carbon dioxide gas. Entry ports are made into the abdomen for the camera and instruments. After isolating the kidney, it is enclosed by a bag to aid removal through another incision. The hand-assisted laparoscopic technique entails an incision large enough to allow insertion of the surgeon's hand to assist with the laparoscopic procedure.

Generally, the left kidney is preferred due to the longer left renal vein; however, the right kidney may be used successfully if preferred or if there are extra arteries on the left. The presence of more than one artery can make the surgery more complicated. It is important that this is established pre-transplant and the donor is counselled of the relevant risks.

The kidney is carefully exposed, and meticulous dissection is carried out with careful handling of the kidney and careful exposure of the renal vein and artery. The gonadal and adrenal tributaries of the renal vein are ligated and divided; often, a posterior lumbar vein needs ligating and dividing as well. The renal artery is cleaned and exposed at its junction with the aorta and the ureter is identified and dissected down to the pelvic brim or just below, where it is ligated and divided. It is very important to avoid too much dissection in the hilum of the kidney, and it is also essential to avoid stripping the ureter of its adventitia. The blood supply to the ureter normally comes from the renal artery, branches from the gonadal vessels and the external iliac artery, and branches of the superior vesicle artery. In a transplant kidney the blood supply to the ureter is entirely dependent on the renal artery, and it is essential to keep a good amount of adventitia around the ureter to allow the blood to reach the distal ureter. One of the major complications after transplantation is ischaemia of the lower end of the ureter, and this is normally due to stripping of the ureter or loss of a lower pole artery at the time of the donor surgery.

When the kidney is free and attached just by the artery and the vein, the artery is ligated and divided first, followed by the vein. The kidney is removed and placed in iced saline, where perfusion is started immediately and, after careful inspection, any further dissection is carried out and a renal biopsy is taken.

POST-OPERATIVE MANAGEMENT: LIVING DONOR

The post-operative care for the living donor is similar to the care given for a conventional nephrectomy. Laparoscopic nephrectomy is associated with a shorter hospital stay, reduced pain, and quicker recovery time than standard nephrectomy. In most centres, patient-controlled analgesia using an opiate is utilised. See BTS (2018) guidelines for more detailed information.

HYDRATION: FLUID AND ELECTROLYTE BALANCE

Paralytic ileus may occur as a result of the retroperitoneal dissection and the handling of the bowel. Therefore, intake of oral fluids must commence slowly and only increase as ileus resolves and bowel sounds are evident. In practice, hydration is maintained by intravenous infusion until oral intake is sufficient. Close monitoring of fluid and electrolyte balance is necessary until dietary intake is adequate.

The passing of urine may prove difficult due to the pain of movement and anxiety, so often a urinary catheter is inserted under anaesthetic so that urinary output can be closely monitored and pain minimised. The catheter is usually removed on the second post-operative day. Regular midstream urine specimens should be obtained for microscopy, culture, and sensitivity during hospitalisation. Monitoring of urine output is important to determine the function of the remaining kidney.

WOUND MANAGEMENT

Wound management should include regular inspection to exclude complications of bleeding and infection.

EMOTIONAL SUPPORT

During the early post-operative period, emotional support should be offered, as should frequent information regarding the progress of the recipient. Donor and recipient should be reunited at the earliest opportunity and encouraged to spend time together. The donor may experience a feeling of

anticlimax after the surgery due to a release of the pre-operative tension and anticipation. Such anticlimax may combine with post-anaesthetic 'blues' to form a mild depression with emotional lability. Staff should recognise the altruism of the act and offer understanding and reassurance.

DISCHARGE

The majority of living donors will be discharged between the third and fourth post-operative day. It is recommended that they continue their post-operative recovery at home for approximately 6 weeks to 2 months. The time before returning to work will depend on type of employment and its physical and psychological demands. Physical monitoring may include one or two further assessments by the surgical team.

The minimum standard includes a follow-up appointment within 4–6 weeks after donation at the transplant centre and an annual review thereafter, either at the transplant centre, the referring nephrology unit, or in primary care. Additional reviews are arranged if clinically indicated. Within a maximum of 12 weeks, it is anticipated that the donor will have made a full recovery and returned to normal activities (BTS 2018). Emotional support should continue as appropriate, with help available if difficulties arise.

Reimbursement for the financial cost of donation such as loss of earnings and travel expenses is available via NHS England (NHS England 2022). The intention is to ensure the process of becoming a living donor has no financial incentive or disincentive.

There are some challenges in achieving life-long follow-up for all donors, particularly for non-UK residents. This is especially the case in countries where living donor transplantation is not an established practice or where individuals pay for healthcare. These donors must be provided with written advice about appropriate annual monitoring.

INCREASING DONOR ORGAN SUPPLY

The Organ Donation Taskforce was formed by the Department of Health in 2008 to look at ways to increase organ donation. The UK at that time had the eighth lowest rate of organ donation in Europe (16.4 donors per million population in 2010) compared with 32.0 in Spain, the highest rate in Europe. Several positive outcomes resulted from the taskforce recommendations, leading to an increase in the number of deceased organ donors:

- Infrastructure to support organ donation and transplantation was improved by the implementation of the SNOD and the Clinical Lead in Organ Donation (CLOD) roles.
- The National Organ Retrieval Service (NORS) was implemented.
- Living kidney donor strategies were developed and implemented.
- DCD donor programmes expanded.

A further strategy was developed in 2020 by NHSBT in conjunction with all four of the UK Health Departments that aimed to build on the work of the organ donation taskforce and to address the specific issues of low consent rates for donation among Black and minority ethnic (BAME) donor families and the wide variation among UK units in the acceptance and usage of donor organs.

Together these strategies have led to a 95% increase in deceased donors and 58% increase in deceased donor transplants since 2008 (NHSBT 2017). There are, however, still opportunities to increase these numbers further (see Table 9.2).

Table 9.2 Actual deceased organ donors across Europe in 2021.

Country	Deceased donors per million population in 2021
Greece	5.0
Switzerland	19.1
Sweden	19.3
Republic of Ireland	13.0
Poland	10.5
Netherlands	15.9
Germany	11.1
United Kingdom	19.8
Slovakia	10.9
Finland	22.2
Czech Republic	25.0
Belgium	26.9
Norway	17.5
Italy	24.0
Austria	20.2
France	24.7
Portugal	29.6
Spain	40.8

Source: EDQM (2022).

The publication of *Organ Donation and Transplantation 2030: Meeting the Need* (NHSBT 2021) aims to build on the success of previous strategies with a 10-year plan to improve the rates of donation, transplantation and organ utilization. The strategy includes the following:

- Use public information campaigns.
- Promote within diverse communities.
- Improve training for NHS staff.
- Develop service sustainability within donation and transplantation.

Achieving these objectives will require a commitment from several areas: from society and individuals, from NHS staff working in areas related to donation and transplantation, and from NHS commissioners and NHSBT (NHSBT 2021).

LEGISLATION

One of the biggest changes affecting organ donation rates is the introduction of opt-out legislation. Since 2015 in Wales, 2019 in Scotland and Jersey, 2020 in England, and 2022 in Northern Ireland, consent legislation has changed so that people are considered to be organ donors after their death unless they have decided not to donate or are in one of the excluded categories. In practice, families are still involved in the consent process before donation can go ahead.

This change has undoubtedly led to an improvement in consent for deceased donation in the UK; however, there are still challenges, and the consent rate is still some way off the best that can be achieved. It is hoped that the strategies set out in the latest strategy will go towards closing this gap.

PRE-OPERATIVE MANAGEMENT FOR A RECIPIENT OF A KIDNEY TRANSPLANT

THE TRANSPLANT CALL

Transplant recipients report mixed reactions of relief, excitement, anxiety, and sadness when they receive the transplant phone call – relief that the waiting time may be over; excitement for the new life ahead; anxiety that the surgery may be difficult or that the transplant may fail; and sadness that a family elsewhere has experienced tragedy in order for the kidney to become available.

During the telephone conversation, the recipient is informed that a transplant may be possible and to travel to

BOX 9.11**NURSING ADMISSION
PROCEDURE**

The nurse will get the following information from the recipient:

- Blood pressure, pulse, temperature, respirations
- Current weight: dry weight
- Past medical history – kidney disease
- Dialysis history – current practice and date and time of last dialysis
- Current health status – recent relevant health events (i.e. blood transfusion/infections)
- Normal urine output, if any
- Social information
- Allergies

The nurse will then attach the name band on the recipient's wrist.

the transplant centre and have nothing further to eat or drink. Brief questions are also asked to clarify current health status and to exclude any infections or other problems that may prevent transplantation.

Some centres contact two recipients for each transplant so that should a positive cross-match (where the recipient cells react to the donor cells) occur for one, a second recipient is already prepared, thus minimising the cold ischaemia time. It has been found that contacting two recipients can lead to repeated disappointments, anger, and depression; therefore, it is preferable to only call one recipient to the transplant centre in the first instance.

NURSING ADMISSION

Upon arrival, the recipient and family are welcomed by the nursing team and helped to familiarise themselves with the unit. Brief information is given regarding the forthcoming blood and clinical tests; questions are answered and anxieties explored during the nursing admission procedure (Box 9.11).

MEDICAL ASSESSMENT

Immediate medical assessment and blood tests are required to assess fluid and electrolyte status (as dialysis may be needed prior to surgery); also to complete the final tissue

BOX 9.12**MEDICAL ASSESSMENT
PROCEDURE**

- Medical history
- Kidney disease history
- Dialysis history
- Current health status – recent relevant events
- Allergies
- Medical examination
- Blood tests:
 - Urea and electrolytes
 - Liver function tests
 - Tissue typing cross-match
 - Viral screen (as in pre-transplant assessment)
 - Cross-match for 2–4 units of blood available for transplant surgery
- Clinical tests:
 - Chest X-ray
 - ECG
 - Midstream specimen of urine, urinalysis

typing cross-match test, if required. Therefore, the medical assessment immediately follows the nursing admission procedure (Box 9.12).

PRE-OPERATIVE DIALYSIS

The results of the medical assessment and blood tests will determine the need for dialysis. Fluid overload and electrolyte imbalance (particularly hyperkalaemia) must be corrected, as they represent an anaesthetic risk and may enhance post-transplantation difficulties.

Haemodialysis with minimal or no heparinisation is often necessary to ensure optimal weight and to reduce fluid overload and serum potassium levels.

Peritoneal dialysis patients may require rapid exchanges to achieve optimal fluid and electrolyte status. The peritoneal catheter exit site should be examined for any signs of infection and a swab taken for culture and sensitivity. Also, following the necessary exchanges, the catheter should be drained and a fluid specimen sent for microscopy, culture, and sensitivity and then the catheter capped, leaving the patient empty of peritoneal dialysis fluid.

INFORMATION AND EMOTIONAL SUPPORT

During the dialysis time, it is often possible to explore individual fears and anxieties and offer emotional support and information regarding post-operative medications and procedures. Recipients are often emotionally labile at this time ('tears and laughter') and require much emotional understanding and support.

IMMEDIATE PRE-OPERATIVE CARE

It is usual for the physiotherapist to visit to commence chest physiotherapy and advice regarding post-operative mobility and for the anaesthetist to perform an assessment. Once the tissue typing cross-match has proved negative, the final pre-operative preparation begins (Box 9.13).

SURGICAL TECHNIQUE FOR KIDNEY TRANSPLANTATION

Before transplantation begins, a catheter is placed into the bladder. This allows drainage of the bladder during the

BOX 9.13

PRE-OPERATIVE PREPARATION

- Skin swabs – for MRSA screening
- Swabs and dressings to other dialysis lines (i.e. permanent central venous catheters)
- Suppositories (if required)
- Bath/shower/hair wash
- Operation gown
- Marking and dressing (to protect) arteriovenous fistula from inadvertent use of invasive monitoring (e.g. intravenous lines, blood pressure cuffs) and to maintain warmth, thus avoiding clotting
- Antithrombosis stockings
- Pre-operative medications such as immunosuppression, aspirin

Note: Transplant centres may use differing combinations of immunosuppressive medications. Medications given immediately pre-operatively.

- Premedication
- Diabetes mellitus: sliding-scale insulin as appropriate

transplant operation and also allows the bladder to be filled with solution containing antibiotics to facilitate later identification of the bladder for reimplantation of the ureter. The right or left iliac fossa is the normal site for the transplant (Figure 9.6).

- An incision is made curving from just above the pubic symphysis to just above the iliac crest.
- The inferior epigastric vessels are ligated and divided, and an extraperitoneal approach is made down on to the iliac vessels.
- The external iliac artery and vein are freed and small branches or overlying lymphatics are ligated and divided.
- Clamps are applied to the external iliac vein and the renal vein is anastomosed to the external iliac vein with continuous 5.0 Prolene sutures.
- Clamps are then applied to the external iliac artery and the renal artery on its patch (known as the Carrell patch) is anastomosed with continuous 5.0 Prolene to the external iliac artery (Figure 9.7). Sometimes the internal iliac artery is used and an end-to-end anastomosis is performed.
- Once the anastomoses are complete, the clamps are released, taking the venous clamps off first. The kidney normally perfuses quickly and one is often able to see immediate urine production.

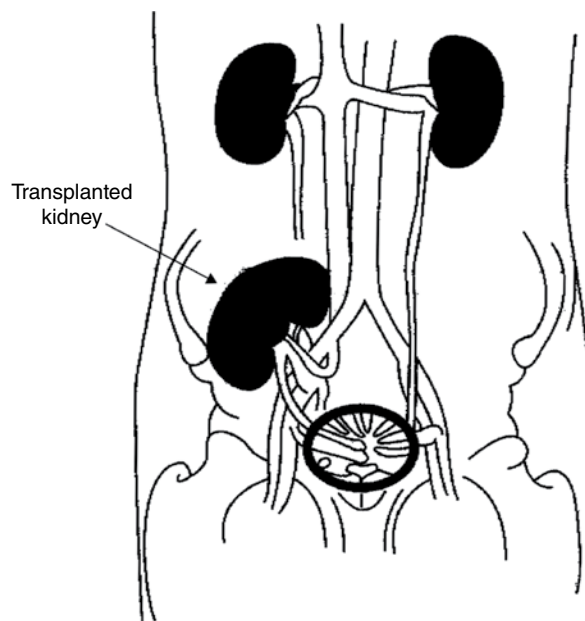


FIGURE 9.6 Position of the transplanted kidney.

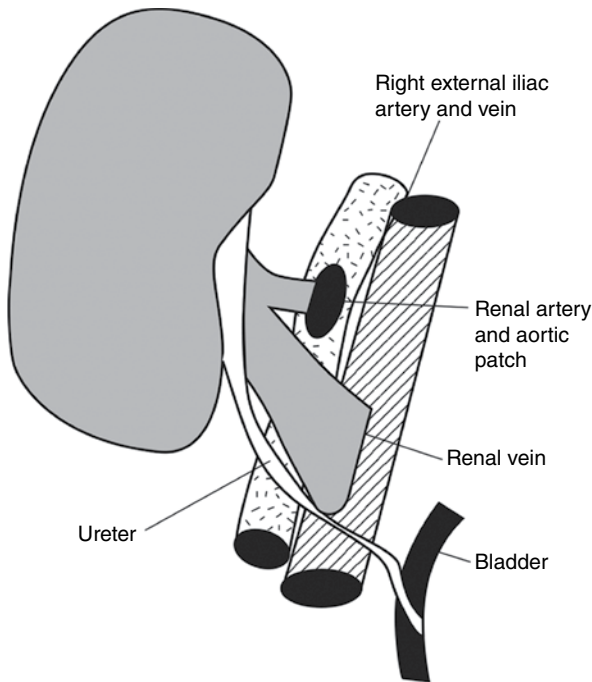


FIGURE 9.7 The surgical technique for kidney transplantation.

- The bladder is then filled through the catheter and the ureter put into the bladder and then tunnelled submucosally to prevent urinary ureteric reflux (the Leadbetter–Politano technique). Most centres may use an extra vesicle technique which involves splitting the muscle, laying the ureter just above the bladder mucosa and so into the bladder, and closing the muscle over the top. If the bladder has been opened it is closed with two layers of Vicryl. A ureteric stent is placed in the ureter and left in situ for 2–6 weeks. This reduces the risk of ureteric stenosis.
- The wound is closed in the usual fashion and the bladder washed out at the end of the procedure.

IMMUNOSUPPRESSION REGIMES

Until 1997, the most commonly used immunosuppression was a ‘triple-therapy’ regime involving ciclosporin (Sandimmun/Neoral), azathioprine (Imuran), and prednisolone. The advent of newer drugs has allowed centres to use differing combinations to ‘tailor’ immunosuppressive medications to individual recipients based on their risk of potential problems post-transplant, such as rejection, diabetes, nonadherence, and cancer. Immunosuppressive regimes are generally divided into induction

(given at the time of transplant) and maintenance, with maintenance immunosuppression divided further to the early (less than 3–6 months) and late (more than 6 months) post-operative period. The aim of all immunosuppression protocols is to reduce rejection, maximise patient and graft survival, and to minimise adverse side effects. The early post-operative period is when the risk of rejection is highest; therefore, this is the time of maximum immunosuppression. Combinations of immunosuppressive medications are given in order to minimise side effects of one particular drug whilst gaining adequate immunosuppressive effect. Guidelines give examples of immunosuppressive regimens dependent on immunological risk (risk of rejection) (NICE 2017; Renal Association 2017). Broadly, they are as follows:

- Induction therapy should be given to all recipients, IL2-RA for those in the low risk group, T-cell depleting antibody (TDA) to be considered for those in the high-risk group.
- Maintenance immunosuppression with a CNI, an anti-proliferative agent (mycophenolate/azathioprine), plus or minus steroids for low and medium risk.
- Mycophenolic acid (MPA) based drugs is given in preference to azathioprine as an antiproliferative agent.
- Steroid avoidance/withdrawal can be used in the first post-operative week in low-risk recipients.

GUIDANCE FROM THE NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

The National Institute for Health and Care Excellence (NICE) updated guidance to the NHS in England and Wales on the use of immunosuppressive therapy for kidney transplantation in adults in October 2017 (NICE 2017). The guidance recommends: interleukin-2 receptor antagonist (IL2-RA, basiliximab) for induction treatment. This should be used with a combination of a CNI and an antiproliferative agent. NICE (2017) recommends tacrolimus and mycophenolate mofetil as the most clinically and cost-effective options.

This guidance represents the views of NICE, and health professionals are expected to take it into account when exercising clinical judgement. However, it does not override the individual responsibility of health professionals to make appropriate decisions for patients. In practice, individual transplant units design immunosuppressive protocols to suit their patient population based on the best available clinical evidence.

INDUCTION IMMUNOSUPPRESSION

Interleukin-2 receptor antagonist (IL2-RA): basiliximab (simulect)

Action Basiliximab works by binding specifically to part of the interleukin-2 receptor, which is only expressed on activated T lymphocytes. Basiliximab helps to prevent proliferation of antigen-stimulated T cells and is used in combination with other immunosuppressives to form a baseline therapy.

Side effects None have been reported.

Anti-CD52 lymphocyte depleting monoclonal antibody: alemtuzumab (campath)

Action Alemtuzumab targets the CD52 antigen present on neutrophils and lymphocytes. It showed potential in reducing rejection with a comparable safety profile to that of Basiliximab. However due to lack of long-term data on safety and efficacy it is not in general use in UK transplant centres apart from a few exceptions where it is used off-licence.

Rituximab (mabthera)

Action Rituximab targets the CD-20 B cell antigen and is used in cancer treatment. Its use in transplantation is often in desensitisation protocols prior to incompatible transplantation, often in combination with extra-corporeal antibody removal therapy (e.g. plasmapheresis).

T-Cell depleting antibodies (TDA)

Action Inhibit and destroy circulatory lymphocytes through antibody action. TDAs are used as induction immunosuppression in high immunological risk recipients and as a treatment for rejection.

Antithymocyte globulin (ATG) – polyclonal antibody

Side effects

- Rash
- Fever/chills
- Anaphylaxis
- Thrombocytopenia/leukopenia
- Myalgia

MAINTENANCE IMMUNOSUPPRESSION

CALCINEURIN INHIBITORS

Tacrolimus (adoport, prograf, advagraf, envarsus)

Tacrolimus is a macrolide antibiotic that inhibits T-cell activation by inhibiting calcineurin. Its action inhibits interleukin-2 and other cytokines that cause early T-cell activation. It is available in an immediate release and prolonged release formulation.

Absorption Tacrolimus is absorbed with variable efficiency by different individuals; therefore, regular monitoring of whole blood levels is necessary. The usual therapeutic range may be higher during the early post-transplant period, with maintenance doses aimed at lower levels. Therapeutic monitoring is usually by 12-hour post-dose trough levels. It may take up to 1 month to stabilise levels post-transplant and continual monitoring is necessary at every clinic visit thereafter.

Side effects Common side effects include:

- visual and neurological disturbances;
- hypertension;
- tremor, headache, insomnia;
- raised blood sugar level;
- leukopenia.

Ciclosporin (neoral/sandimmune)

Ciclosporin is a natural peptide found in two strains of fungi. It was first introduced into clinical immunosuppression in 1983 and is a CNI. Neoral ciclosporin is in a micro-emulsion and is more reliably absorbed.

Action Ciclosporin inhibits interleukin-2 and interferes with the growth and activation of T lymphocytes.

Side effects Usually, side effects are dose dependent and responsive to dose reduction. The most common side effects include:

- nephrotoxicity – decreased GFR;
- hypertension;
- hepatic dysfunction;
- hirsutism;
- hyperlipidaemia;

- hyperkalaemia;
- hyperuricaemia;
- gum hypertrophy;
- hypomagnesaemia;
- hypertrichosis.

Other less common side effects include:

- muscle weakness;
- thrombocytopenia.

Absorption: as with tacrolimus, regular monitoring of whole blood levels is necessary.

ANTIPROLIFERATIVE AGENTS

Mycophenolate mofetil (MMF), mycophenolic acid (MPA) and enteric-coated mycophenolate sodium (Myfortic) are antiproliferative agents.

Mycophenolate mofetil (MMF)

Mycophenolate mofetil was licenced in 1995; it is metabolised to mycophenolic acid (MPA). It has a more selective action than that of azathioprine.

Action Mycophenolate mofetil acts by preventing activated lymphocytes from differentiating and proliferating and thereby limiting clonal expansion. In the United Kingdom, this drug was previously used in preference to azathioprine in selected patients who were considered to be at a higher risk of rejection than average; however, it is now recommended as the first-line anti-proliferative in preference to azathioprine.

Side effects

- Gastrointestinal effects include diarrhoea, constipation, nausea, vomiting.
- Blood disorders include leukopenia, anaemia, pancytopenia.

Mycophenolate mofetil is known to cause congenital abnormalities and spontaneous miscarriage. For this reason, female recipients are advised to use at least one method of contraception whilst on treatment and to continue for 6 weeks after treatment. Male recipients are advised to ensure contraception with a female partner whilst on treatment and for 90 days after discontinuation of the drug.

A formulation of MPA (Myfortic) is available with an enteric coating that some patients may find reduces gastrointestinal side effects.

Azathioprine

Azathioprine is a derivative of the anticancer drug 6-mercaptopurine and was introduced into clinical practice in 1962.

Action Azathioprine inhibits both DNA and RNA synthesis and prevents growth of lymphocytes.

Side effects The main side effect is neutropenia. If the white blood cell count (WBC) drops to below $3.5 \times 10^9 \text{ l}^{-1}$, the dose should be reduced. If the WBC continues to fall the drug should be stopped temporarily.

Other side effects include:

- alopecia;
- general malaise;
- muscular pains;
- malignancy;
- pancreatitis (rare);
- altered liver function;
- cholestatic jaundice (rare).

Because of the risk of neutropenia, blood counts must be checked at intervals of no longer than 3 months.

CORTICOSTEROIDS

Prednisolone

Action The action of corticosteroid preparations is complex and involves anti-inflammatory responses with blocking of T cells and interleukin-1.

Side effects

- cushingoid appearance;
- fluid retention;
- glaucoma;
- increased appetite;
- hypertension;
- psychosis;
- peptic ulceration;
- increase in blood sugar levels.

Side effects with long-term treatment:

- subcapsular cataract;
- pancreatitis;
- skin thinning;
- osteoporosis.

Many centres start steroid reduction at 1 month after transplant and aim to remove steroid therapy at 1 year after transplant because of the long-term side effects.

Mammalian target of rapamycin inhibitor (M-Tori) sirolimus (rapamycin)

Sirolimus acts later in the T-cell activation than CNIs. It inhibits interleukin-2-mediated signal transduction pathways. Sirolimus is not nephrotoxic, which gives it an advantage over CNIs. It was licenced for use in the UK in 2001. Due to its potential to delay healing, sirolimus is rarely used in the early post-transplant period. It also interacts with CNI to enhance toxicity, so careful monitoring is required if used in combination with these drugs.

Side effects

- delayed healing (lymphocoele);
- hypercholesterolaemia;
- hypertriglyceridaemia;
- thrombocytopaenia;
- increased blood levels of MPA;
- nose bleeds.

Everolimus Everolimus is similar to sirolimus but has a shorter half-life and therefore a shorter time to achieve steady state concentration. Toxicity and side effects are similar to sirolimus, particularly the interaction with CNI.

Belatacept (Nulojix)

Action Belatacept is a fusion protein that works by selectively blocking the process of T-cell activation. Licenced in the United Kingdom in 2011 for use in combination with corticosteroids and mycophenolate in maintenance immuno-suppression, belatacept is given by intravenous infusion according to a dosing schedule commencing on the day of transplant, then on day 5, week 2, 4, 8, and 12. Subsequent maintenance regime comprises monthly infusions. Initial evidence suggested improved patient and graft survival and improved kidney function with belatacept when compared to ciclosporin (Vincenti et al. 2016).

However longer-term data indicated higher rates of rejection and the drug is not recommended for use in transplantation (NICE 2017).

KIDNEY TRANSPLANT REJECTION

There are three types of kidney transplant rejection:

- hyperacute rejection;
- acute rejection;
- chronic rejection or chronic allograft injury (CAI).

HYPERACUTE REJECTION

Hyperacute rejection (Figure 9.8) occurs rapidly, within minutes or hours of revascularisation of the transplant. It is caused by:

- Presence of preformed cytotoxic antibodies in the recipient's blood reacting against the donor's histocompatibility antigens. This is caused by previous failed transplants, blood transfusions, or pregnancies.
- ABO incompatibility exists between the donor and the recipient.

The final lymphocytotoxic cross-match prior to transplant should demonstrate that cytotoxic antibodies are present and transplantation should not take place; thus, a hyperacute rejection is a very rare phenomenon today.

Hyperacute rejection may be observed during the transplant surgery. Instead of the kidney becoming distended and pink as the arterial and venous clamps are released, as is usual, with hyperacute rejection the kidney will remain flaccid and become blue. Damage is almost always irreversible and the graft is lost.

ACUTE REJECTION

Acute rejection (Figure 9.9) can be cellular and/or antibody-mediated rejection (AMR), which commonly occurs between 4 days and 2 months after transplantation. Rejection is ideally diagnosed by biopsy of the graft in order to differentiate from other causes of graft dysfunction such as CNI toxicity or BK virus nephropathy. Acute cellular rejection is usually treated initially with corticosteroids; usual practice is to administer daily bolus doses of 500 mg intravenous methylprednisolone over a 3-day period (one bolus each day). Cellular rejection that does not respond to treatment with high-dose steroids and rejection that is antibody mediated is treated with a course of TDA. Rejection often responds to treatment; however, a severe rejection episode may result in some loss of overall

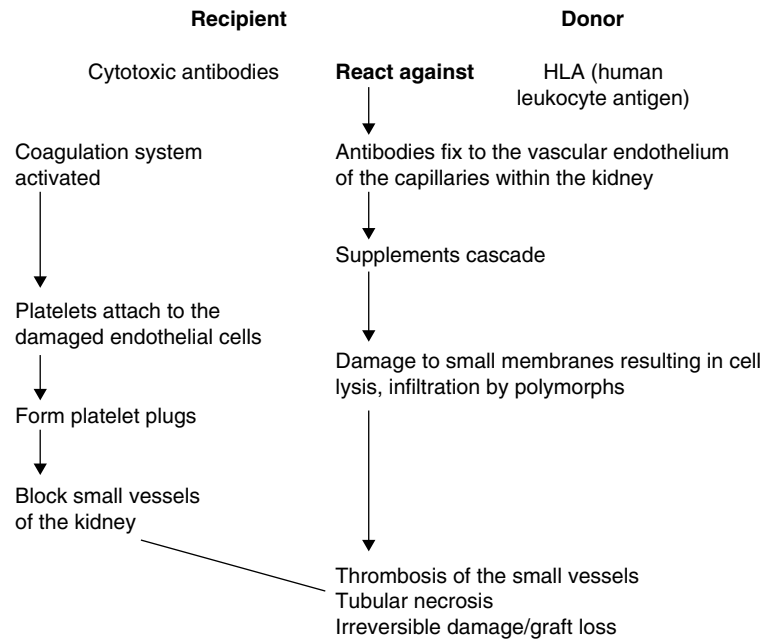
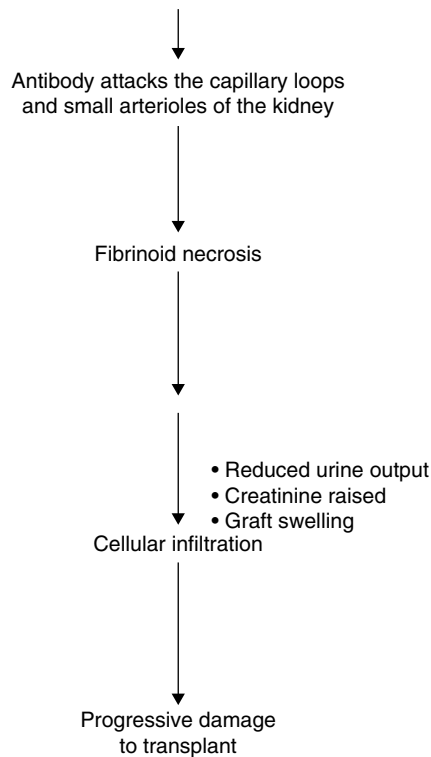


FIGURE 9.8 Histopathology of hyperacute rejection.

Antibody-mediated rejection



Cellular rejection

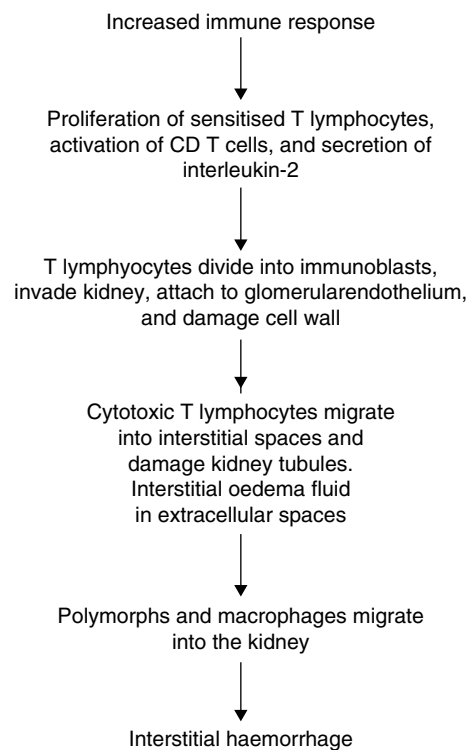


FIGURE 9.9 Histopathology of acute rejection.

graft function. It is usual to increase the level of maintenance immunosuppression following an episode of rejection unless nonadherence or another reason for reduced levels of immunosuppression can be confirmed.

TRANSPLANT BIOPSY

A percutaneous biopsy of the transplant kidney is often the only reliable way to diagnose accurately the cause of graft dysfunction. Many patients are anxious about the biopsy procedure and the effect on the transplanted kidney and will require reassurance and explanation of the rationale for the procedure and the procedure itself. Many centres now perform biopsies as day case procedures, minimising hospital stay and disruption for the patient.

It is recommended practice to send serum samples at the time of biopsy to check for the presence of donor HLA specific antibodies. This can aid the diagnosis of AMR and ensure the correct treatment is given. Biopsy samples should be routinely stained for C4d deposition (to indicate AMR) and SV40 antigen (BK virus), as appearances can be similar on histological examination.

Some centres perform 'protocol biopsies' that is, routine biopsies at set time periods post-transplant (e.g. at 3, 6, or 12 months) with the aim of optimising immunosuppressive regimes based on the results.

CHRONIC ALLOGRAFT INJURY

Chronic allograft injury (CAI) usually occurs over months or years but may occur much earlier. It is difficult to separate out the contribution of rejection from other factors detrimental to the kidney. The term *chronic allograft injury* encompasses all of these, meaning that permanent damage is seen on biopsy. There is a gradual occlusion of the lumen of the arteries of the kidney with interstitial fibrosis which destroys the graft. The exact mechanisms involved in CAI are still unclear and may be immunological or nonimmunological. Other factors include donor history and delayed graft function, acute rejection episodes, hypertension, CNI toxicity, and infection. The first signs of CAI are usually a gradual worsening of kidney function with proteinuria.

POST-OPERATIVE CARE AND COMPLICATIONS FOR THE RECIPIENT OF A KIDNEY TRANSPLANT

AIMS OF CARE

The aim of post-operative management is to provide the appropriate care to support primary transplant function and to aid optimal recovery. Initial care involves close

monitoring of physical and psychological health, with frequent assessments and adjustments in response to changes in health status.

IMMEDIATE POST-OPERATIVE CARE

In most cases the anaesthetist will insert an arterial line and a triple-lumen central venous line immediately prior to surgery. This facilitates accurate monitoring of arterial pressure and fluid status and allows infusion of fluids and medications during surgery and in the early post-operative phase.

CARDIORESPIRATORY STATUS

Immediate baseline observations should be recorded, including blood pressure, pulse, respirations, and temperature. Such observations should continue every 30 minutes until stable and thereafter hourly or as appropriate. Twenty-four-hour ECG monitoring may be routine; however, in some centres such monitoring may only be used for patients in high-risk categories. Close monitoring of respiratory status is essential, as anaesthetic drugs and analgesia may be poorly excreted due to reduced kidney function, thus depressing respiratory effort and increasing the risk of pulmonary complication. Early chest physiotherapy is essential.

PAIN MANAGEMENT

The experience of pain is unique to each individual and therefore the use of patient-controlled analgesia is a suitable therapy as it will provide satisfactory pain management, reduce recipient anxiety, and facilitate deep breathing and movement. An opiate derivative is commonly used. Due to the potential risks of opiate toxicity in people with kidney disease, many transplant units use a variety of pain management techniques including transversus abdominis plane (TAP) block and infiltration of local anaesthetic. These methods have been shown to reduce post-operative pain and opiate requirements after abdominal surgery with minimal complications and high patient satisfaction (McDonnell et al. 2007). Recipients often report that the presence of the urinary catheter causes the greatest discomfort. Severe pain in the graft in the early post-operative period may be indicative of swelling of the kidney as a result of venous thrombosis.

HYDRATION: FLUID AND ELECTROLYTE BALANCE

Inadequate hydration may adversely affect transplant function; therefore, the maintenance of an acceptable venous pressure without the complication of fluid overload

is an integral element of care. Fluid intake is usually administered through the central venous line. CVP measurements, recorded hourly, and urinary output measurements, recorded hourly, are used as a guide to appropriate fluid intake.

Fluid intake protocol usually involves fluids being administered through an infusion pump with hourly intake equal to the previous hour's output plus 50 ml, with the aim of achieving a target mean arterial pressure (MAP).

Peripheral line perfusion must also be included in the intake total. Infusion of dopamine may be introduced to help maintain pressure and improve transplant perfusion by reducing vasoconstriction of the smaller renal vessels. Monitoring of serum biochemistry and haemoglobin levels is ongoing and the results will determine the type of intravenous fluid given. Often 5% dextrose is alternated with normal saline. Blood transfusion is occasionally required.

Oral fluids are usually introduced within the early post-operative phase (as paralytic ileus is rare) then nutrition as tolerated and gradually increased as appropriate.

URINE OUTPUT: CATHETER CARE

A urinary catheter will be in situ following the transplant surgery, and the urine may be bloodstained due to the surgical procedures to the bladder and ureter. Clot formation may occur, resulting in pain and anuria. Gentle sterile bladder washouts can be performed to alleviate the problem and re-establish urine flow.

Twenty-four-hour urine output should be recorded, and it is, of course, important to note the volume of urine passed from the native kidneys pre-transplantation when assessing urinary totals. Daily urine analysis and biochemistry should be noted, and daily catheter specimens obtained for microscopy, culture, and sensitivity. The catheter is usually removed on the fifth post-operative day. Some recipients may experience difficulty with voiding and also may have very limited bladder capacity due to pre-transplant bladder atrophy. Reassurance and bladder retraining strategies usually help to solve these problems.

WOUND MANAGEMENT

A wound drain may be present, and drainage should be monitored. Observation and aseptic dressing of the wound will be given as appropriate, and the sutures removed when healing has occurred. The immunosuppression regime and other contributory factors such as diabetes or malnutrition may impede the healing process.

INFECTION CONTROL

Recipients are immunocompromised and therefore infection control procedures should be strictly followed. Handwashing should take place before and after each nursing and medical procedure and visitors should be monitored for infections. Medications should include prophylaxis against infection and additional treatments should be commenced if infection is suspected.

The recipient should be helped to achieve personal and oral hygiene of a high standard and aseptic techniques utilised with regard to wound, peritoneal catheter site, urinary catheter and CVC care. Catheter tips should be cultured for microscopy and sensitivity when removed.

POST-OPERATIVE MEDICATIONS

In addition to immunosuppressive medications, other medications are required post-transplant:

- antibiotic prophylaxis – particularly to prevent infection with *Pneumocystis carinii*;
- PPIs;
- nystatin to prevent oral candidiasis;
- aspirin, to minimise long-term cardiovascular risk;
- statin, to minimise cardiovascular risk;
- calcium supplements, to limit side effects of corticosteroids on bone mineral density;
- isoniazid, for prophylaxis against TB if required;
- valganciclovir, for prophylaxis against CMV infection/re-activation if required.

CONTINUING CARE

Recipients usually recover quickly from the anaesthetic and begin early mobilisation to prevent complications. A light diet is introduced on day one. Constipation may be a problem due to anaesthetic, immobility and analgesia, and gentle laxatives or suppositories may be needed. Self-care is usually achieved by the fifth post-operative day.

Sadness may be linked to thoughts of the donor family, and grief and guilt may be expressed that the transplant has resulted from 'another's tragedy'. It is often helpful to give recipients anonymous details such as age and gender of the donor, and to offer them the opportunity to write a letter of thanks to the donor family. The expression of thanks usually enables recipients to accept the gift of the organ and to move forward to their new lifestyle.

Anxiety is usually linked to the fear of complications such as rejection, infection, and graft loss. Recipients and their families require considerable support, understanding, and in-depth information during the early post-operative phase, particularly if difficulties occur.

COMPLICATIONS OF KIDNEY TRANSPLANTATION

Renal dysfunction – acute tubular necrosis

The most common cause of delayed graft function after kidney transplantation is ATN, which may be due to prolonged hypotension in the donor or prolonged ischaemia during the donor or recipient surgery. Dialysis support may be required until adequate transplant function is achieved. Haemodialysis, with reduced heparinisation, can be undertaken as necessary (a frequent clotting screen will be required), and peritoneal dialysis recommenced as long as the peritoneum has not been breached by surgery.

CNIs (ciclosporin, tacrolimus) are known to be nephrotoxic and may therefore prolong ATN.

Acute rejection

Many transplant recipients will experience at least one episode of acute rejection. Acute rejection may not present with overt symptoms; a mild increase in creatinine, indicating graft dysfunction, may be the only symptom, often picked up following a routine visit to the transplant clinic.

The clinical signs of acute rejection may include:

- renal dysfunction;
- pyrexia;
- reduced urine output;
- swelling and tenderness of the transplant;
- ankle oedema, weight gain;
- flulike symptoms.

Vascular complications

Transplant renal artery and renal vein thrombosis Thrombosis of the renal artery or renal vein is a rare complication. Clinical signs of graft thrombosis usually include pain in the graft, renal dysfunction, anuria, and hypotension. Diagnosis may be confirmed by ultrasound scanning (see Chapter 7). Immediate surgical exploration should be undertaken. In the majority of cases the transplant will be lost.

Transplant renal artery stenosis Renal artery stenosis usually occurs between 6 and 12 months after transplantation.

Signs include graft dysfunction and severe hypertension with a bruit on auscultation over the transplant. Diagnosis is confirmed by doppler ultrasound or angiography. In severe cases intervention may be required either by percutaneous transluminal angioplasty or surgery.

Urological complications

A major urological complication which may occur is avascular necrosis of the distal end of the transplant ureter, resulting in leakage of urine. Surgical reimplantation of the ureter will be required in most cases. This complication has become less common recently due to the use of a ureteric stent.

INFECTIONS

BACTERIAL INFECTION

The clinical signs of infection are similar to those of rejection (pyrexia, tachycardia, flulike illness); therefore, it is important that both possibilities are considered and investigations undertaken to exclude either cause. Transplant recipients are at increased risk of infection due to immunosuppression, however, due to their impaired immune response, they may not display overt signs of infection until the infection has become more serious. It is therefore vital to monitor transplant recipients closely for signs and symptoms of infection and to investigate even seemingly innocuous symptoms. Infections in this group of patients can be life threatening if not treated appropriately and adequately. Prophylaxis against tuberculosis should be initiated post-transplant for patients at risk (Yuan et al. 2023).

Chest infections may result from *Pneumococcus*, *Haemophilus influenzae*, *Klebsiella*, and *Pneumocystis*. Infection may develop rapidly, resulting in the need for ventilation. Early treatment with appropriate antibiotic therapies is essential.

FUNGAL INFECTIONS

Oral *Candida* is common, and many centres give antifungal prophylaxis for a short time following transplantation. Oral hygiene of a high standard should be encouraged. Genital *Candida* may also occur and recipients may be reluctant to report this problem. Recipients should be informed that *Candida* is a potential problem, and that treatment will be required.

Transplant recipients are at increased risk of serious fungal infections such as *Aspergillus*, *Cryptococcus*, and *Pneumocystis carinii*.

VIRAL INFECTIONS

Cytomegalovirus (CMV)

CMV infection is usually acquired during childhood and early adulthood and is a minor flulike illness. However, this minor illness can cause major complications in the immunosuppressed transplant recipient. CMV disease, after transplantation, may occur because of:

- Latent disease is reactivated in a CMV-positive recipient. Such reactivation is generally classed as 'secondary CMV'.
- CMV is transmitted from a CMV-positive donor to a CMV-negative recipient through the transplanted organ, or community acquired infection after the transplant. This is classed as 'primary CMV'.

CMV may also be transmitted through whole blood transfusions, hence many centres require that all patients receive CMV-negative blood.

CMV vaccinations for all transplant recipients in the pre-transplant phase would be an ideal solution to this problem but as yet, no clinically acceptable vaccines have been formulated. Also matching so that CMV-negative recipients receive CMV-negative grafts would help to minimise the difficulties experienced, but such matching is rarely possible in practice. Therefore, primary CMV disease does occur and can cause significant morbidity and mortality.

The usual time for manifestation of CMV disease is 4–8 weeks post-transplantation. Clinical signs include swinging pyrexia, rigours, malaise, and, in extreme cases, pneumonitis, retinitis, gastroenteritis, and encephalitis.

Valganciclovir is widely used as prophylaxis in high-risk recipients (such as CMV-negative recipients receiving CMV-positive grafts, or CMV-positive recipients receiving ATG).

Recipients are monitored for serological evidence of CMV activity and treated according to local guidelines. Oral valganciclovir is widely used for treatment, although it is licenced only for prophylaxis; however, if the patient is unwell, admission to hospital and treatment with IV ganciclovir may be necessary. Recently novel therapies have become available that offer further management strategies for treatment of CMV (Kotton and Kamar 2023).

Herpes simplex and varicella zoster virus

Herpes simplex (types I and II) can cause problems following transplantation. Oral and anogenital lesions may occur. Recipients may be reluctant to report such problems due to anxiety and embarrassment. Therefore, recipients should be aware that these lesions may arise and that they occur

because of reduced immunity, not because of other social issues. Sympathetic and understanding care should be offered and antiviral treatment commenced.

Reactivation of latent VZV may also occur and present as classical 'shingle' lesions. Antiviral treatment is necessary to prevent systemic complications. Disseminated VZV (chickenpox) is dangerous in immunosuppressed patients, resulting in some cases of life-threatening illness with encephalitis, pneumonitis, and meningitis. Recipients must be aware of the problems associated with such viral infections and should be encouraged to report signs and symptoms or contact with infected others.

BK (polyoma) virus

Most BK virus infections are asymptomatic but it is implicated in ureteric stenoses, late haemorrhagic cystitis, and deteriorating graft function. Two factors may account for the increase in BK nephropathy: improvements in biopsy interpretation and the newer immunosuppressants now widely used. Presence of BK virus in biopsy samples can be confirmed by testing with SV40 staining. Infection is associated with deteriorating kidney function but can often be controlled by reducing immunosuppression. BK virus is often detected during routine urinalysis; haematuria can be a sign of BK infection and urine should be sent to the laboratory for cytological examination. This will detect the presence of viral cells. This does not always indicate the presence of active virus in the graft and a serum sample tested for BK virus load can indicate the presence and the activity of the virus. Serological testing of viral counts is a useful tool to monitor the effect of reduction in immunosuppression following a diagnosis of BK virus nephropathy at biopsy. Transplant centres now routinely monitor recipients post-transplant for the presence of BK viraemia in the blood. Treatment strategies for BK virus infection remain elusive but there is some evidence that tailored immunosuppression regimens could minimise the risk of primary BK virus infection and re-infection following re-transplant (Mallet et al. 2017).

DISCHARGE OF THE RECIPIENT FROM HOSPITAL AND CONTINUING CARE

If recovery has been uncomplicated, the transplant recipient may be discharged home on about the fifth post-operative day.

Educative and developmental intervention is very important for recipients of transplants. They must have sufficient knowledge to monitor their health status, be understanding of medication regimes, and report problems

if they arise. Assessment of learning difficulties should be completed soon after transplant so that relevant interventions may be implemented to aid learning, knowledge, and eventual independence. Physical barriers such as impaired sight and hearing can be aided by electronic blood pressure monitoring equipment. Language and literacy difficulties can be resolved with diagrammatic information, translations, and medication presented in daily dosette boxes, all promoting personal independence, although family members may be included in teaching sessions as appropriate.

The nurse may assess learning abilities (with an informal, nonthreatening discussion) post-transplant and plan a teaching information programme, implement this programme, and evaluate progress. Information is given as appropriate both verbally and in the form of a written information booklet. At the time of discharge the recipient should have the following knowledge (Box 9.14).

Drug charts and monitoring booklets should be utilised as part of a self-medication programme introduced as recovery allows or on the second post-operative day.

Immediately after discharge, recipients will be seen very frequently in the out-patient clinic. It is important that nursing intervention identifies developmental needs so that the recipient's knowledge base continues to expand and psychosocial care is offered. Reports suggest that some recipients feel that only the kidney function and transplant progress is monitored, not the rehabilitation of the 'whole person'.

Therefore, holistic care is essential, addressing psychosocial needs with physical needs; such care may be most appropriately offered by a transplant nurse practi-

tioner who can offer continuity of care as well as understanding and support.

The aim of ongoing care is to empower the recipient to achieve optimal individual rehabilitation. It is essential to help the recipient achieve a balance between monitoring health and gaining normality. One of the most important post-transplant psychosocial tasks that the recipient needs to accomplish is the gradual relinquishing of the sick role and the eventual return to nonpatient status. Medical and nursing staff can give a confusing message by referring to recipients as patients and demanding strict adherence to rigid health protocols, whilst at the same time insisting that transplantation offers a return to 'normality'.

Flexibility of care, understanding, and encouragement are required to enable recipients to take control of their lives and achieve the highest quality of life possible. Ongoing health monitoring will continue and problems may occur, but advice and support should be available throughout the complete transplant experience.

ONGOING CARE: INFORMATION AND SUPPORT FOR TRANSPLANT RECIPIENTS

- *Peritoneal dialysis catheter.* If present at the time of transplant, the peritoneal dialysis catheter is often removed during the transplant operation. Leaving the catheter in place to be removed at a later date can increase the risk of infection post-transplant as the recipient will be in an immunosuppressed state. The ureteric stent is usually removed endoscopically 2–4 weeks after transplant, although some transplant surgeons attach the stent to the urinary catheter at the time of surgery, allowing the stent to be removed with the catheter. This practice may reduce the incidence of post-transplant urinary tract infection due to early removal of the stent and avoidance of the need for a further invasive procedure.
- *Diet.* A normal diet should be followed but care taken with weight gain due to increased appetite and freedom from the kidney diet. If cholesterol or lipid levels are raised, dietary restrictions may be necessary. (See Chapter 12).
- *Vaccinations and travel.* Transplant recipients should not receive live vaccines. Therefore, it is important to consult the transplant centre before travel immunisations are given. Foreign travel is encouraged as part of resuming normal activities after a transplant, but many centres advise recipients to avoid travel abroad for the first 12 months after transplant. This is to ensure the recipient has access to specialist medical care during the first year after transplant when the risks of complications such as rejection and infection are higher.

BOX 9.14

RECIPIENT PREDISCHARGE KNOWLEDGE

- Understand the action, dosage, and side effects of medication and the need for adherence.
- Be aware of how and where to obtain repeat prescription for all medications.
- Recognise the signs of potential complications such as rejection and infection and ensure awareness of how and when to alert transplant personnel in light of any of these changes.
- Have telephone numbers of the transplant centre and know how to contact staff.
- Ensure aware of arrangements for follow-up and the importance of regular attendance.

- **Skin care.** Immunosuppression predisposes recipients to skin damage from trauma and sun and increases the risk of skin malignancies. Therefore, dermatological monitoring and advice should be given and recipients should use high-factor sunblock during sun exposure and should report any skin lesions. Many centres refer their patients for a baseline dermatological assessment after transplantation.
- **Fertility.** Female patients should be aware of fertility issues and be given advice with regard to birth control measures. Barrier methods or the mini-pill are the most appropriate therapies, but intrauterine devices can be useful. Recipients of both sexes should be informed of the specific risks related to mycophenolate mofetil. In general, all recipients should, ideally, wait at least 1 year before considering pregnancy and advice should be available with regard to pregnancy risks in individual cases (Wiles et al. 2019). Patients of both sexes must be told that they should inform the clinic if they have any plans for pregnancy, so that any medical issues or drug changes can be discussed. Recipients cannot breastfeed after delivery as the immunosuppression may transfer to the baby.
- **Employment.** Recipients may return to work as soon as they feel able as long as graft function and health are satisfactory and employment does not put either at risk. Help should be available for those recipients seeking employment.
- **Health education.** Smoking is discouraged due to the risk of enhanced cardiorespiratory and vascular complications. Exercise and activity are encouraged, although contact sports such as rugby or martial arts may put the graft at risk. Female patients should have regular cervical smears and breast examinations due to the increased risk of malignancy. Male patients should be monitored for potential malignancies and encouraged to perform testicular self-examination.
- **Psychological health.** Psychological support should be available to help with sexual problems, body image problems and marital problems.
- **Social needs.** Help and advice should be available for social needs such as benefits, housing, and return to work.

SIMULTANEOUS PANCREAS-KIDNEY TRANSPLANTATION (SPK)

Pancreatic transplantation is of proven clinical benefit for patients with type-1 diabetes who are undergoing kidney transplantation, and is usually carried out at the same time, as simultaneous pancreas-kidney transplant (SPK).

The procedure has an increased mortality and morbidity risk due to the complexity of the surgery but for those patients suitable to undergo the procedure the long-term benefits often outweigh these risks.

Barlow et al. (2017) reported that recipients of both pancreas and kidney transplants (SPK) from 2001 to 2014 ($n = 1739$) resulting in a functioning pancreas graft had significantly better kidney graft and patient survival than those with just a kidney graft ($n = 385$) or those with a failed pancreas graft. However, the authors found that kidney-pancreas grafts for recipients with type-1 diabetes do not confer an overall survival advantage compared with kidney-only transplants.

SPK transplantation can not only restore kidney function and allow freedom from dialysis but enables discontinuation of insulin and retardation of the complications of diabetes. Immunosuppression for kidney-pancreas transplantation is similar to that for kidney alone.

Survival rates post-SPK transplant in the UK are:

- Patient survival at 1 year is 98% and at 5 years 91%.
- Graft survival at 1 year is 94% and at 5 years 82%.

Figure 9.10 shows pancreatic transplant activity in the UK, with the number of patients registered on the SPK waiting list at 278 on 1 March 2022.

The pancreas is a fragile gland and is easily damaged by trauma, poor perfusion, or duct obstruction. Surgical placement of the pancreas is determined by the need to allow drainage of the pancreatic enzymes. Drainage may be either into the bladder, with vascular connections to the external iliac artery and vein, or, more commonly, into the duodenum. Enteric drainage can avoid the problems associated with bladder drainage such as dysuria, haematuria, metabolic acidosis. Patients with a neurogenic bladder can develop 'reflux pancreatitis' from inadequate bladder emptying. In the post-transplant period, urinary tract infections are common and pancreatic enzyme activation can lead to 'chemical' cystitis or urethritis in those with bladder drainage. Patients may subsequently develop urethral stricture or disruption, haematuria, or perforation of the bladder or duodenum. Urinary drainage, however, allows monitoring of amylase excretion in the urine, which may offer the ability to detect pancreas rejection early. Transplantation of a pancreas and a kidney from the same donor allows manifestations of kidney allograft rejection to guide treatment as kidney graft rejection is believed to precede or parallel pancreas rejection. Surgical problems related to exocrine pancreatic drainage and allograft pancreatitis are usually due to leakage or fistula formation leading to fluid collections, pseudocysts, or abscesses surrounding the pancreatic graft.

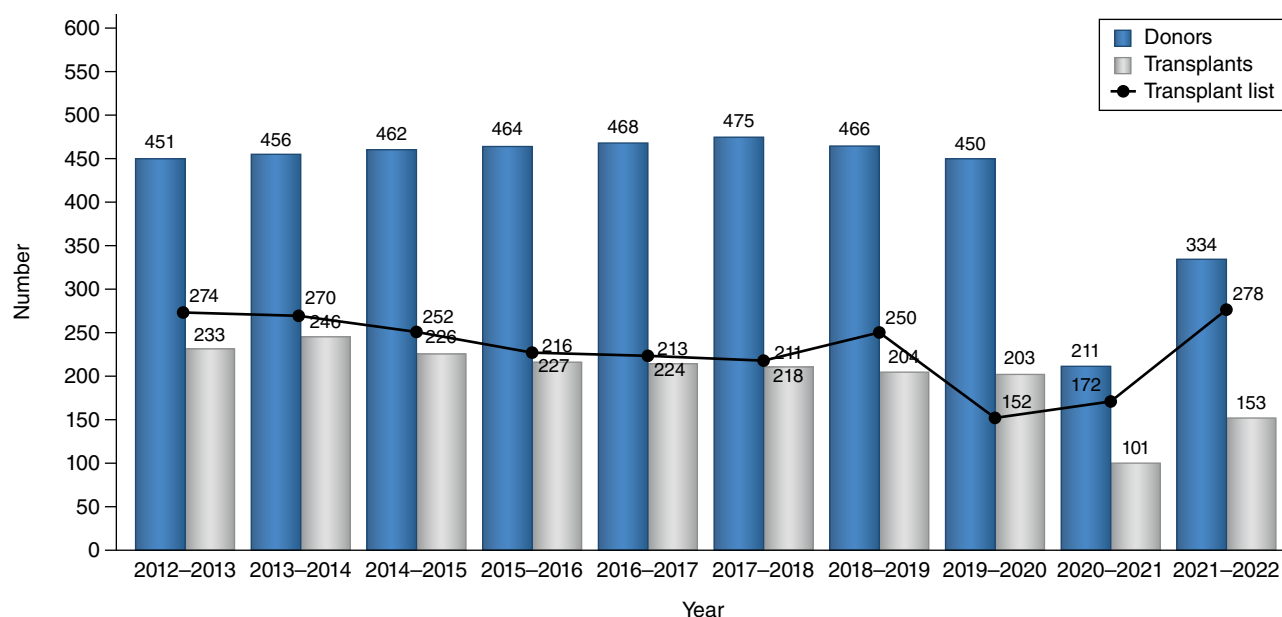


FIGURE 9.10 Deceased pancreas and islet programme in the United Kingdom, 1 April 2012–31 March 2022. Source: from: *Transplant Activity in the UK 2021–2022*. NHS Blood and Transplant.

Causes of pancreas graft loss include vascular thrombosis, pancreatitis, infection, and rejection. Vascular thrombosis may occur, in part, because of the low circulatory flow through the pancreas but can also accompany pancreatitis or rejection. Hyperamylasaemia is common after transplantation and may be either asymptomatic or indicative of symptomatic pancreatitis.

Patients with type-2 diabetes have relative contraindications for pancreatic transplant – they are usually older by the time end-organ damage develops and may have significant vasculopathy. Despite this, there is some evidence that SPK transplantation offers benefits to this group of patient, with outcomes comparable to type-1 diabetics and to kidney transplantation alone (Fu et al. 2021; Gruessner et al. 2017). The results of these studies however are often

from single centres and are from non-UK transplanting centres or registry data. It is possible that the restricted selection of type-2 candidates for SPK has affected these results, so further studies are required to confirm whether there truly is a benefit in offering this option to this group of patients.

CONCLUSION

A successful kidney transplant can provide the best quality of life for those with ESKD. This chapter has discussed the ever-evolving clinical care and management for people who have donated and also received kidney transplants. Nurses working in transplantation are advised to keep abreast of newly published evidence-based guidelines in order to provide the best and safest care they can.

REFERENCES

- Academy of Medical Royal Colleges (2008). A code of practice for the diagnosis and confirmation of death. https://aomrc.org.uk/wp-content/uploads/2016/04/Code_Practice_Confirmation_Diagnosis_Death_1008-4.pdf (accessed 20 February 2023).
- Barlow, A.D., Saeb-Parsy, K., and Watson, C.J.E. (2017). An analysis of the survival outcomes of simultaneous pancreas and kidney transplantation compared to live donor kidney transplantation in patients with type 1 diabetes: a UK transplant registry study. *Transplant International* 30 (9): 884–892.
- Batabyal, P., Chapman, J., Wong, G., Craig, J.C., Tong, A. (2012). Clinical practice guidelines on wait-listing for kidney transplantation: consistent and equitable? *Transplantation* Oct 15; 94(7): 703–713.
- Belaiche, S., Décaudin, B., Dharancy, S. et al. (2017). Factors relevant to medication non-adherence in kidney transplant: a systematic review. *International Journal of Clinical Pharmacy* 39 (3): 582–593.
- Bryan, C.F., Nelson, P.W., Shield, C.F. et al. (2007). Long-term survival of kidneys transplanted from live A2 donors to O and B recipients. *American Journal of Transplantation* 7 (7): 1181.

- BTS (2015). Addendum to the UK Guidelines for Living Donor Kidney Transplantation. British Transplantation Society. <https://bts.org.uk/guidelines-standards>
- BTS (2018). Guidelines for living donor kidney transplantation. https://bts.org.uk/wp-content/uploads/2018/07/FINAL_LDKT-guidelines_June-2018.pdf (accessed 20 February 2023).
- Byrne, C., Caskey, F., Castledine, C. et al. (2017). UK Renal Registry 19th Annual Report of the Renal Association. *Nephron* 137 (suppl1): 13.
- Canaud, G., Audard, V., Kofman, T. et al. (2012). Recurrence from primary and secondary glomerulopathy after renal transplant. *Transplant International* 25: 812–824.
- Chadban, S.J. et al. (2020). KDIGO Clinical practice guideline on the evaluation and management of candidates for kidney transplant. *Transplantation*. 104 (4S1):p S11–S103.
- Chaudhry, D., Chaudhry, A., Javeria, P., Sharif, A. (2022) Survival for waitlisted kidney failure patients receiving transplantation versus remaining on waiting list: systematic review and meta-analysis. *BMJ* 376 doi: <https://doi.org/10.1136/bmj-2021-068769>
- Collaborative Transplant Study (2023). Collaborative Transplant Study <https://www.ctstransplant.org/> (CTS-K-21001-Feb2023).
- EDQM(2022). Newsletter Transplant: International figures on donation and transplantation 2017. Vol 27. <https://www.edqm.eu/en/newsletter-transplant>
- Department of Health (2010). *Organ Donor Campaign Report: Faith and Organ Donation*. London: Department of Health.
- Dudley, C. and Harden, P. (2011). Assessment of the Potential Kidney Transplant Recipient. Renal Association <http://www.renal.org/Clinical/GuidelinesSection/AssessmentforRenalTransplantation.aspx> (accessed 21 October 2017).
- ERA Registry: ERA Registry Annual Report (2020). Amsterdam UMC, location AMC, Department of Medical Informatics, Amsterdam, the Netherlands. <https://www.era-online.org/wp-content/uploads/2022/12/ERA-Registry-Annual-Report2020.pdf> (accessed 20 February 2023).
- Fellner, C.H. and Marshall, J.R. (1968). Twelve kidney donors. *Journal of the American Medical Association* 206: 2703.
- Fournier, C., Pallet, N., Cherqaoui, Z. et al. (2012). Very long-term follow-up of living kidney donors. *Transplant International* 25 (4): 385–390.
- Fu, Y., Cao, Y., Wang, H., Zhao, J., Wang, Z., Mo, C., Shi, X., Feng, G. & Song, W. (2021). Metabolic outcomes and renal function after simultaneous kidney/pancreas transplantation compared with kidney transplantation alone for type 2 diabetes mellitus patients. *Transplant International*. 34 (7): 1198–1211.
- Ghaly, M. (2012). Religio-ethical discussions on organ donation among Muslims in Europe: an example of transnational Islamic bioethics. *Med Health Care Philos.* 15 (2): 207–220.
- Gibbons A, Bayfield J, Cinnirella M, et al. (2021). Changes in quality of life (QoL) and other patient-reported outcome measures (PROMs) in living-donor and deceased-donor kidney transplant recipients and those awaiting transplantation in the UK ATTOM programme: a longitudinal cohort questionnaire survey with additional qualitative interviews *BMJ Open*. 11: e047263. doi: 10.1136/bmjopen-2020-047263
- GMC (2022). Treatment and care towards the end of life: good practice in decision making. General Medical Council. Available at: <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life> (accessed 20 February 2023)
- Gruessner, A.C., Laftavi, M.R., Pankewycz, O., Gruessner, R.W.G. (2017). Simultaneous pancreas and kidney transplantation-is it a treatment option for patients with type 2 diabetes mellitus? An analysis of the international pancreas transplant registry. *Current Diabetes Reports*. 17 (6): 44.
- Guardian (1999). NHS took organs donated for whites only. <https://www.theguardian.com/uk/1999/jul/07/race.world> (accessed 23/6/23)
- Harvard Medical School (1968). Report of the ad hoc committee of Harvard Medical School to examine the definition of brain death. Definition of irreversible coma. *JAMA* 205: 337.
- Holscher, C.M., Leanza, J., Thomas, A.G. et al. (2018) Anxiety, depression, and regret of donation in living kidney donors. *BMC Nephrol* 19: 218.
- HTA (2023) *HTA Code of Practice. Guiding Principles and the Fundamental Principle of Consent*. Human Tissue Authority. <https://www.hta.gov.uk/guidance-professionals/codes-practice-standards-and-legislation/codes-practice> (accessed 23 June 2023).
- Hulme, W., Allen, J., Manara, A.R. et al. (2016). Factors influencing the family consent rate for organ donation in the UK. *Anaesthesia* 71 (9): 1053–1063.
- Human Tissue Act, Chapter 30. (2004). © The Crown. https://www.legislation.gov.uk/ukpga/2004/30/pdfs/ukpga_20040030_en.pdf. (accessed 20 February 2023).
- Jankowski, J., Floege, J., Fliser, D., Böhm, M., Marx, N. (2021). Cardiovascular disease in chronic kidney disease. Pathophysiological insights and therapeutic options. *Circulation*. 143 (11): 1157–1172.
- Jaramillo, A., Reddy, K., Sudhakar, M.B.B.S., Heilman, R. (2020). Using the virtual crossmatch to allow for safer and more efficient kidney transplantation of highly sensitized patients. *Transplantation*. 104 (6): 1121–1122.
- Johnson, R.J., Fuggle, S.V., O'Neill, J. et al. (2010). Factors influencing outcome after deceased heart beating donor kidney transplantation in the United Kingdom: an evidence base for a new national kidney allocation policy, on behalf of the kidney advisory group of NHS Blood and Transplant. *Transplantation* 89 (4): 379–386.
- Kaballo, M.A., Canney, M., O'Kelly, P., Williams, Y., O'Seaghdha, C.M., Conlon, P.M. (2018). A comparative analysis of survival of patients on dialysis and after kidney transplantation. *Clinical Kidney Journal* 11 (3): 389–393.
- Kemph, J.P. (1966). Renal failure, artificial kidney and kidney transplant. *The American Journal of Psychiatry* 122: 1270.

- Kotton, C.N., Kamar, N. (2023) New Insights on CMV Management in Solid Organ Transplant Patients: Prevention, Treatment, and Management of Resistant/Refractory Disease. *Infect Dis Ther*. 12 (2): 333–342.
- Krishnan, N., Mumford, L., Lipkin, G., Gill, P., Fletcher, S., Dasgupta, I., Ryan, R., Raymond, N. (2020). Comparison of medium-term outcomes of living kidney donors with longitudinal healthy control in the United Kingdom. *Transplantation*. 104 (3): e65–e74.
- MacNeill, S.J., Casula, A., Shaw, C. et al. (2016). UK Renal Registry 18th annual report: Chapter 2 UK renal replacement therapy prevalence in 2014: national and Centre-specific analyses. *Nephron* 132 (Suppl 1): 41–68.
- Mallat, S.G., Tanios, B.Y., Itani, H.S., Lotfi, T., McMullan, C., Gabardi, S., Akl, E.A., Azzi, J.R. (2017). CMV and BKPyV Infections in Renal Transplant Recipients Receiving an mTOR Inhibitor-Based Regimen Versus a CNI-Based Regimen: A Systematic Review and Meta-Analysis of Randomized, Controlled Trials. *Clin J Am Soc Nephrol*. 12 (8): 1321–1336.
- Marck, C.H., Neate, S.L., Skinner, M. et al. (2016). Potential donor families' experiences of organ and tissue donation-related communication, processes and outcome. *Anaesthesia and Intensive Care* 44 (1): 99–106.
- Margreiter, C., Resch, T., Oberhuber, R. et al. (2013). Combined pancreas-kidney transplantation for patients with end-stage nephropathy caused by type-2 diabetes mellitus. *Transplantation* 95 (8): 1030–1036.
- McDonnell, J.G., O'Donnell, B., Curley, G., Heffernan, A., Power, C., and Laffey, J.G. (2007). The Analgesic Efficacy of Transversus Abdominis Plane Block After Abdominal Surgery: A Prospective Randomized Controlled Trial. *Anesthesia and Analgesia* 104 (1): 193–197.
- Muller, E., Botha, F.C.J., Barday, Z.A., Manning, K., Chin-Hong, P., Stock, P. (2021). Kidney Transplantation in HIV Positive Patients: Current Practice and Management Strategies. *Transplantation* 105 (7): 1492–1501.
- Naylor, K.L., Kim, S.J., Kuwornu, J.P., Dixon, S.N., Garg, A.X., McCallum, M.K., Knoll, G.A. (2022). Pre-transplant maintenance dialysis duration and outcomes after kidney transplantation: A multicenter population-based cohort study. *Clinical Transplantation* 36 (3).
- NHS Blood and Transplant (2024). An Islamic perspective on organ donation. <https://www.organdonation.nhs.uk/helping-you-to-decide/your-faith-and-beliefs/islam/>.
- NHS England (2022). Commissioning Policy: Reimbursement of Expenses for Living Donors. NHS England. Available at: <https://www.england.nhs.uk/publication/commissioning-policy-reimbursement-of-expenses-for-living-donors/> (accessed 20 February 2023).
- NHS England (2017). Service specifications. Adult kidney transplant. <https://www.england.nhs.uk/wp-content/uploads/2017/05/service-spec-adult-kidney-transplant-service.pdf> (accessed 20 February 2023).
- NHSBT (2014). Living Donor Kidney Transplantation 2020: A UK Strategy. https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/1434/ldkt_2020_strategy.pdf (accessed 20 February 2023).
- NHSBT (2022a). Organ Donation and Transplantation Activity Report 2021/22. <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/27108/activity-report-2021-2022.pdf> (accessed 20 February 2023).
- NHSBT (2022b). POL 186/14 Kidney Transplantation: Deceased Donor Organ Allocation. ODT Clinical, Policies and guidance. <https://www.odt.nhs.uk/transplantation/tools-policies-and-guidance/policies-and-guidance/> (accessed 20 February 2023).
- NHSBT (2022c). Clinical contraindications to approaching families for possible organ and tissue donation. POLICY POL 188/16. <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/28307/pol188-16.pdf> (accessed 19 February 2023).
- NHSBT (2022d). Potential donor audit. <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/28061/annual-pda-report-1-april-2021-31-march-2022.pdf> (accessed 20 February 2023).
- NHSBT (2022e). Donor optimisation. <https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/donor-optimisation/> (accessed 20 February 2023).
- NHSBT (2022f). Consent and authorisation: Clinical guidance around gaining consent and authorisation from a donor family. <https://www.odt.nhs.uk/deceased-donation/best-practice-guidance/consent-and-authorisation/> (accessed 20 February 2023).
- NHSBT (2021). New UK strategy sets out ambition to be world leaders in organ donation and transplantation. <https://www.nhsbt.nhs.uk/news/new-uk-strategy-sets-out-ambition-to-be-world-leaders-in-organ-donation-and-transplantation/> (accessed 20 February 2023).
- NHSBT (2017). Taking organ transplantation to 2020. <https://www.odt.nhs.uk/odt-structures-and-standards/key-strategies/archived-strategies/taking-organ-transplantation-to-2020/> (accessed 20 February 2023).
- NICE (2019). Venous thromboembolism in over 16s; reducing the risk of hospital-acquired deep vein thrombosis or pulmonary embolism. NICE guideline (NG89). Last updated 13 August 2019. <https://www.nice.org.uk/guidance/ng89> (accessed 18 April 2024).
- NICE (2018). Renal replacement therapy and conservative management. NICE guideline [NG 107] <https://www.nice.org.uk/guidance/ng107/chapter/Recommendations#preparing-for-renal-replacement-therapy-or-conservative-management> (accessed 23 June 2023).
- NICE (2016). Organ donation for transplantation: improving donor identification and consent rates for deceased organ donation. NICE Clinical guideline [CG 135]. <https://www.nice.org.uk/guidance/cg135> (accessed 29 June 2023).
- NICE (2017). Immunosuppressive therapy for kidney transplant in adults. National Institute for Health and Care Excellence. <https://www.nice.org.uk/guidance/ta481> (accessed 20 February 2023).
- Ralph, A.F., Chadban, S.J., Butow, P., Craig, J.C., Kanellis, J., Wong, G., Logeman, C. and Tong, A. (2020). The experiences and

- impact of being deemed ineligible for living kidney donation: Semi-structured interview study. *Nephrology*, 25: 339–350.
- Renal Association (2017). Post-operative care in the kidney transplant recipient. https://bts.org.uk/wp-content/uploads/2017/06/FINAL_PostOperative_Care_Guideline.pdf (accessed 20 February 2023).
- Roland, M.E.; Barin, B., Huprikar, S., Murphy, B., Hanto, D. W., Blumberg, E., Olthoff, K., Simon, D., Hardy, W. D., Beatty, G., Stock, P. G. (2016). The HIVTR Study Team. *AIDS* 30(3): 435–444.
- SaBTO (2020). Microbiological safety guidelines. Department of Health. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/876161/SaBTO-microbiological-safety-guidelines.pdf (accessed 20 February 2023).
- Schrieber, B., Abdelrahilm, M., Abudayyeh, A., and Murakami, N. (2022). Emerging concepts in managing malignancy in kidney transplant patients. *Seminars in Nephrology* 42(1): 63–75.
- Smith, M.D., Kappell, D.F., Province, M.A. et al. (1986). Living related kidney donors: a multicentre study of donor education, socioeconomic adjustment and rehabilitation. *American Journal of Kidney Diseases* 8: 223.
- Stoumpos, S., Jardine, A.G., and Mark, P.B. (2014). Cardiovascular morbidity and mortality after kidney transplantation. *Transplant International* 28 (1): 10–21.
- Sumit R.M. Gokoel, Kim B. Gombert-Handoko, Tom C. Zwart, Paul J.M. van der Boog, Dirk Jan A.R. Moes, Johan W. de Fijter. (2020) Medication non-adherence after kidney transplantation: A critical appraisal and systematic review. *Transplantation Reviews*. 34 (1).
- Terasaki, P.I., Cecka, J.M., Gjertson, D.W. et al. (1997). Spousal and other living donor transplants. In: *Clinical Transplants 1997* (ed. J.M. Cecka and P.I. Terasaki), 269–284. Los Angeles, USA: UCLA Tissue Typing Laboratory.
- Timmerman, L., Timman, R., Laging, M., Zuidema, W.C., Beck, D.K., IJzermans, J.N.M., Busschbach, J.J.V., Weimar, W. and Massey, E.K. (2016). Predicting mental health after living kidney donation: The importance of psychological factors. *Br J Health Psychol* 21: 533–554.
- UKDEC (2011). An Ethical Framework for Controlled Donation after Circulatory Death. UK Donation Ethics Committee. www.aomrc.org.uk/wp-content/uploads/2016/05/Controlled_donation_circulatory_death_consultation_0111.pdf (accessed 18 April 2024).
- UK Renal Registry (2023). UK Renal Registry 25th Annual Report – data to 31/12/2021, Bristol, UK. <https://ukkidney.org/audit-research/annual-report> (accessed 23 June 2023).
- Vincenti, F., Rostaing, L., Grinyo, J. et al. (2016). Belatacept and long-term outcomes in kidney transplantation. *NEJM* 374: 333–343.
- Wang, L.W., Masson, P., Turner, R.M., Lord, S.W., Baines, L.A., Craig, J.C., Webster, A.C. (2015) Prognostic Value of Cardiac Tests in Potential Kidney Transplant Recipients. *Transplantation*. 99 (4): 731–745.
- Watson, C.J., Johnson, R.J., Mumford, L. (2020). Overview of the Evolution of the UK Kidney Allocation Schemes. *Current Transplantation Reports* 7: 140–144.
- Welsh Government (2017). Evaluation of the Human Transplantation (Wales) Act: Impact Evaluation Report. <https://www.gov.wales/evaluation-human-transplantation-wales-act-impact-evaluation> (accessed 18 April 2024).
- Wiles, K., Chappell, L., Clark, K. et al. (2019). Clinical practice guideline on pregnancy and kidney disease. *BMC Nephrol* 20, 401.
- Yuan, Z., Chao, S., Xu, Y., Niu, Y. (2023). Chemoprophylaxis for the prevention of tuberculosis in kidney transplant recipients: A systematic review and meta-analysis. *Front Pharmacol*. Mar 16;14:1022579.

Non-dialytic Options and a Palliative Conservative Kidney Management Approach

Helen Noble, Claire Carswell, and Ian Walsh

Queen's University Belfast, Belfast, UK

LEARNING OUTCOMES

- to describe the palliative care needs of patients with end-stage kidney disease (ESKD) who follow the non-dialytic, conservative kidney management (CKM) pathway or who withdraw from dialysis.
- to understand the range of symptoms patients with ESKD experience, and how to assess and address them.
- to understand which patients require consideration of their end-of-life care needs.
- to review the role of the kidney nurse when providing palliative and end-of-life care.

INTRODUCTION

This chapter considers the needs of patients with ESKD when their health may be declining and their partners, carers, and families. This is a sensitive time, and for some, the end of their life may be approaching. Both kidney and palliative care specialists continue to identify the significant and growing need for excellent CKM and palliative care within nephrology (Lanini et al. 2022). The focus of the chapter is on those who choose not to dialyse and follow a CKM pathway, but the care of the smaller number of those who withdraw from dialysis is also discussed. Both groups of patients present specific challenges to the nurses caring for them. Kidney nurses may also be asked to help patients and families as they consider the decision for or against dialysis. This is a challenging decision, particularly for those who have multiple comorbid conditions where the benefits of dialysis are less clear (Tavares et al. 2020).

NUMBERS OF PATIENTS

Chronic kidney disease (CKD) is a disease found across the age spectrum but is more commonly seen in older people. The prevalence of stage 1–5 CKD in the UK population is estimated to be 13% (Jain et al. 2023). An estimated 2.6 million individuals aged 16 and above in England are believed to have chronic kidney disease (CKD) stages 3–5, making up approximately 6.1% of this age group's population. Notably, CKD stages 3–5 are more common in women, affecting 7.4% of women compared to 4.7% of men.

A strong correlation exists between age and CKD stage 3–5 prevalence. Specifically, the percentage of individuals with CKD stage 3–5 increases with age:

- Among those aged 64 and younger, approximately 1.9% are estimated to have CKD stage 3–5.
- In the 65–74 age group, this prevalence rises to 13.5%.
- Among individuals aged 75 and over, a significant 32.7% are affected.

Looking ahead, with the current CKD prevalence applied to the aging population, it was anticipated that the prevalence of CKD stage 3–5 would rise to 3.2 million people by 2021 and further increase to 4.2 million by 2036. These projections highlight the growing burden of CKD in the coming years, underscoring the importance of continued monitoring and management of the condition, particularly in the context of an aging population (Public Health England 2014).

While not all these patients will progress to end-stage disease, the numbers requiring kidney replacement therapy (KRT) have been increasing steadily in recent years, as the population ages. Over the last 40 years there have also been many changes which have increased understanding and improved life expectancy for people with ESKD. Medical and technological advances have led to increased availability of treatment for kidney problems and an ability to treat older people who have other illnesses. The UK Renal Registry report (2023) suggests that the number of people on KRT is continuing to rise, with 8,175 adult patients starting kidney replacement treatment for ESKD in the UK in 2021, an increase of 7.3% from 2020, and that older patients treated by haemodialysis make up a disproportionate amount of the numbers accepted for KRT (Byrne et al. 2017).

The need for KRT is also influenced by ageing of ethnic minority populations. These groups have a higher prevalence of kidney problems due to higher rates of diabetes mellitus and hypertension. Between 2011 and 2036, the prevalence of CKD stages 3–5 is expected to increase by 8.3% and will be particularly noticeable within the Black and minority ethnic groups and older people (Public Health England 2014).

THE IMPORTANCE OF CONSERVATIVE KIDNEY MANAGEMENT

The median age of patients starting KRT is 66.4 years, and 16% are over 75 years (Byrne et al. 2017). Worldwide, the use of KRT is expected to double by 2030 (Thaminda et al. 2015). With increased age there is usually increased comorbidity; 67% of those over 65 have one or more comorbidities when commencing dialysis. For those over 85 years, about 30% die within a year of commencing dialysis (Byrne et al. 2017). There are many factors that can influence the treatment choices for these older patients, especially for those over 75 years. Dialysis has been shown to have very limited survival advantage in those with high levels of comorbidity (Garcia Testal 2021) and this, combined with the high burden of treatment with dialysis (Sala et al. 2021),

has led to the development of conservative management pathways (where dialysis is not commenced).

According to a survey conducted by the International Society of Nephrology across 150 countries, 81% of these countries offered conservative management services (Bello et al. 2019). Interestingly, the availability of these services didn't seem to depend on a country's income level. However, high-income countries were more likely to provide conservative management services based on medical advice or patient choice, rather than imposing restrictions on these options.

Accessible conservative management services were only found in 38% of the surveyed countries, and none of these countries fell into the low-income category. Less than half of the countries incorporated multidisciplinary teams (46%), shared decision-making (32%), or provided psychological, cultural, or spiritual support (36%) as part of their conservative kidney management care. Additionally, only a quarter of the countries offered training to their clinicians on delivering these services.

Data on the active involvement of patients in making decisions about conservative kidney management are limited. In one observational study conducted in Australia (Morton et al. 2012), which involved 721 patients with ESKD averaging 80 years of age, it was found that 65% were given the option of conservative management, and ultimately, 14% chose CKM as their treatment.

THE PALLIATIVE APPROACH

Palliative care emerged as a discipline in the 1960s, through the inspiration of Dame Cicely Saunders and others. The World Health Organisation definition of palliative care (World Health Organisation 2020) is widely accepted (see Box 10.1).

It is important to recognise that this definition of palliative care is not disease orientated but patient focused, and also reflects changes made to move away from a disease-specific definition, such as cancer, to an understanding that palliative care should be available to all with a life-threatening illness. It also encompasses early introduction of a palliative approach, while enabling a person to continue with life-prolonging therapies, such as dialysis.

Palliative care aims for a holistic approach to care of patients and families, in situations where the disease is advanced, progressive, and incurable. It encompasses physical, psychological, practical, and spiritual aspects of care, and includes consideration of the needs of families and informal carers. For those with ESKD, it is not always clear what model of palliative care provision should be adopted; whether palliative care should be provided predominantly by kidney professionals, by specialist

BOX 10.1**DEFINITION OF PALLIATIVE CARE (ADAPTED FROM WORLD HEALTH ORGANISATION 2020)**

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care goes beyond just addressing physical symptoms in the context of suffering. It takes a comprehensive approach, involving a team of healthcare professionals who offer complete support to patients and their caregivers. This support covers not only the physical aspects of care but also practical needs and provides bereavement counselling. The primary objective is to establish a support system that enables patients to live as fully and actively as possible until the end of life.

Palliative care is explicitly recognized as an essential component of the universal human right to health. It should be seamlessly integrated into healthcare services, with a strong emphasis on person-centered care that tailors the approach to the specific needs and preferences of each individual.

Opioids are not limited to managing pain; they can also alleviate other distressing physical symptoms, such as breathlessness. Ensuring effective control of these symptoms at an early stage is not only a medical necessity but also an ethical duty to relieve suffering and uphold an individual's dignity in the face of serious illness or at the end of life.

Source: WHO (2020)

palliative care professionals, or by primary care professionals – or (most likely) by some combination of these three groups. Much will depend on the configuration and availability of local services. Palliative care has been, and still is, at different stages of development throughout the world (de Barbieri et al. 2022). It is a dynamic concept that all practitioners should integrate into their daily practice; a patient-centred approach to care in advanced disease with a focus on quality of life and management of symptoms (Quinn et al. 2020). It may be inappropriate to move a person to a different group of healthcare professionals just because of their stage of life. One of the big influences on, and challenges to practice, therefore, is the ongoing integration of the extensive knowledge and experience in palliative care from the specialist palliative care field into nephrology practice, for the benefit of patients and families.

RECENT GOVERNMENT AND OTHER INITIATIVES

Political and national developments in the United Kingdom have given considerable impetus to development of clinical services for those approaching the end of life. In the United Kingdom, nephrology was one of the first specialties to adapt the national End-of-life Care Strategy (Department of Health 2011) and make specific recommendations for the ESKD population. A framework for implementing end-of-life care in advanced kidney disease was produced (NHS Kidney Care 2015). This has had an important impact within kidney units, to ensure that improvements in palliative and end-of-life care for those with advanced kidney disease are

achieved. Information and help can be found on the National Kidney Federation website (NKF 2023).

Internationally, 'The KDIGO Controversies Conference on Supportive Care in CKD' has defined a useful guide to clinical and research activities aimed at improving outcomes in people living with advanced kidney disease. The work includes development of globally relevant guidelines (Davison et al. 2015). In addition, Davison et al. (2019) have detailed recommendations for the care of patients receiving conservative kidney management.

It is important to distinguish between *palliative* and *end-of-life* care. Meghani (2004) cautions against using the terms synonymously; end-of-life care incorporates palliative care, but not all palliative care will be related to end-of-life care. Palliative care interventions, which focus on a holistic approach, may be both appropriate and very helpful throughout the kidney illness from diagnosis and can often markedly improve quality of life in a sustained way. If symptom burden is high and quality of life is poor, despite disease-based interventions, then this is the time to consider palliative care, whatever the expected prognosis.

COMMUNICATION, DECISION-MAKING, AND PLANNING

PATIENT COMMUNICATION

As disease progresses and the end of life approaches, skilled communication becomes increasingly important in the delivery of effective patient care. Communication

between patient and nurse is important. Patients want to know what to expect as their illness advances, and they value professionals who can talk openly about death and dying (Mandel et al. 2017). Contrary to the beliefs of many professionals, openness does not remove hope but helps to focus it in a more realistic way.

Information needs to be delivered at a pace that each individual patient can manage. It is important to ensure there is the time and conditions for difficult questions to be asked and answered, since many factors will prevent such questions being explored. Communication between the patient and their family also becomes increasingly important to patients as death approaches, and nurses have a key role in facilitating this. Sometimes, understandably, family members adopt a protective attitude towards each other, shielding each other from bad news, but this is not always helpful, particularly if the patient is seeking openness and honesty (Bristowe et al. 2019).

Information also needs to be carefully matched to each patient's preference for information and for involvement in decisions. In general, doctors and nurses tend not to raise their concerns about a patient's declining health and worsening prognosis unless a patient asks about this, and patients often wait for professionals to raise such matters. This can lead to a collusion of silence, where both continue to focus on other (often disease-related) issues, and do not address underlying concerns about declining health (Lanini et al. 2022).

At the same time, the patient's choices about end-of-life care need to be explored. If open communication does not occur, choices are likely to be more limited. An example of this is the preference to die at home if possible; this cannot be facilitated if initial communication and discussions about the implications of the illness have not taken place. Box 10.2 provides some suggestions of useful 'opening questions' that nurses can use to help enable a patient or their family to raise their concerns readily.

For patients with ESKD, some specific considerations are important. Firstly, some patients will be living with their kidney condition over a long period of time. It can be more difficult, then, for both patient and professional to perceive the change from living with a long-term condition to a decline in health towards death. If health professionals do not see this change, they may well deny the patient and their family the opportunities they need to understand their illness and address and plan for their remaining time. Secondly, the pattern of decline may be more uncertain than for other terminal conditions such as cancer. The limited available evidence suggests that prognosis in conservatively managed patients varies

BOX 10.2

SUGGESTED QUESTIONS TO EXPLORE PATIENT CONCERNS

How do you think things are going with your health overall?
Have you any worries about your health?
What concerns you most at present?
Have you any worries about the future?
Do you want to know more about your illness and what to expect?
What is most important for you to achieve?
What are your most important hopes?
What are your biggest fears?
What would most improve your quality of life at present?
What is most important to you: quality or length of life?
How is your family handling your illness?
Have you given any thoughts to what treatments you might or might not want in the future?

considerably, depending partly on the underlying cause of the kidney failure and on which other comorbid conditions coexist (Song et al. 2020). Dealing with this uncertainty is hard for both patient and professional, and it needs to be honestly acknowledged in any communication. Thirdly, kidney professionals rightly focus on active disease management. End-of-life care requires a change of focus from a primarily disease-centred approach to a more patient-centred approach. Disease management takes a much lower priority, particularly as the end of life approaches. Controlling symptoms, attending to psychosocial and spiritual needs, and anticipating future care needs all become as important, or more important, than kidney expertise. Nurses may feel uncertain about their skills in this area, particularly if they work with patients at the end of life infrequently.

FAMILY COMMUNICATION

Effective end-of-life care cannot be delivered without good family communication (Lanini et al. 2022). However, the ethical and legal responsibilities of the nurse are predominantly to the patient, so it is important to seek patient agreement before any communication with the family, particularly if that communication takes place away from the patient. In the final days of life, increasing uraemia may mean that patients are often confused, and increasingly lack the ability to make decisions for themselves. It is important, therefore, to ensure from the beginning that relevant family members are involved in any management decisions (if the patient wishes) and that they are aware of

the patient's end-of-life preferences, before the patient becomes less well. O'Hare et al. (2017a) highlights that failing to incorporate family and friends into patient care may not only cause distress but can also result in missed opportunities to improve advance care planning.

COMMUNICATION WITHIN THE TEAM

A number of key decisions will be made with patients as they approach the end of their life. These include decisions around withholding or withdrawing dialysis, decisions around preferred place of care and death, and cardiopulmonary resuscitation (CPR) decisions, amongst others. Each of these should be communicated to the whole kidney team. Patients will often see different professionals at each clinic visit or hospital admission, and it is important that patient and family are given clear and consistent messages.

A wide variety of non-kidney healthcare professionals may also be involved in end-of-life care, ranging from the general practitioner and district nurses to specialist palliative-care professionals (who may be community, hospital, or hospice based). Time and energy therefore need to be devoted to communicating any decisions made to all members of the team, including those providing care out of hours and those who may be called in a crisis, both at home or in hospital.

SHARED DECISION-MAKING

Shared decision-making (SDM) refers to the process of making decisions between two parties where there is an exchange of information and consensus on the option chosen (Charles et al. 1999). SDM is advocated by the Renal Association (2020) and National Institute of Health and Care Excellence (2021) to provide a framework to help support decisions that are shared. SDM in nephrology particularly ESKD is associated with improving a number of outcomes including pain and increasing satisfaction. It can also reduce decisional conflict and improve bereavement outcomes for families and is a patient priority and key area of research (Shi et al. 2022; McPeake et al. 2023).

As disease advances, decisions may be made either to withdraw dialysis or to follow a conservative pathway. This raises complex and challenging issues (Noble et al. 2017; Chen et al. 2022). These issues have been reviewed and guidelines have been developed in the United States to inform dialysis decision-making (Renal Physicians Association 2010). The guidelines are built on shared decision-making, recognising that patients are individuals and have their own history, perspectives, and preferences.

A practical guide for the care of patients with ESKD near the end of life has also been developed (Bansal et al. 2020).

People with kidney disease are known to have widely differing preferences for involvement in decisions, but generally receive less information than they want and have less involvement in decisions than they prefer (Chen et al. 2022). Some nephrologists feel that most, if not all, patients requiring KRT should receive dialysis, but there is growing recognition that, for some patients, dialysis may not greatly increase survival while adding a considerable treatment burden. In one study, up to 19% of patients regretted the decision to commence dialysis (Saeed et al. 2019). For some patients, conservative management (care without dialysis, but with management to minimise disease progression, and full supportive and palliative care) may be a better option, although any final decision will depend on patient preferences as well as professional advice.

Following a conservative management pathway sometimes demands especially difficult decision-making, since it requires weighing up patient preferences, estimated survival on or off dialysis, anticipated quality of life on or off dialysis, and the treatment burden with dialysis. Estimating survival and quality of life is difficult for the individual patient. These factors – including symptom burden, survival, and quality of life – continue to be studied in patients who are managed conservatively (O'Hare et al. 2017b).

ADVANCE CARE PLANNING

Effective and appropriate care can only be delivered by planning ahead and anticipating future care needs, but ACP is not without barriers. These include staff lacking confidence to discuss ACP, finding it difficult to identify opportunities to initiate discussion, and believing they lacked the characteristics needed to discuss ACP. Conflicting perspectives between doctors and nurses over ACP and culture and belief-based barriers to discussing ACP are also obstacles (Chen 2021). It is therefore important to explore sensitively with patients (and their family, if desired) what their wishes are for future care, or in the event of a sudden deterioration or crisis. Relatively few patients choose to write a formal advance directive, but all should be offered the chance to discuss preferences for future care and management. These discussions should be carefully documented and revisited regularly since preferences may change.

Advance directives are written documents which specify a patient's preferences, in anticipation of loss of the capacity to make his or her own decisions, when they are less well. In the United Kingdom, the Mental Capacity Act (2005)

BOX 10.3**THE PRINCIPLES UNDERLYING
THE UK MENTAL
CAPACITY ACT 2005**

- A person must be assumed to have capacity unless it is established that he/she lacks capacity.
- A person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success.
- A person is not to be treated as unable to make a decision merely because he/she makes an unwise decision.
- An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his/her best interests.
- Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

clarifies the legal status of such documents, and also makes provision for a person to be named to represent the patient's preferences in their place (known as Lasting Power of Attorney). The Mental Capacity Act is based on five principles designed to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so. The principles are outlined in Box 10.3.

Whether specific documents or advance directives are used or not, every patient should, as their disease progresses, have the chance to discuss their future care, concerns, hopes, and preferences. The responsibility lies with the professional to ensure that these opportunities arise. These issues should be addressed early and systematically, remembering that both patients and professionals find it hard to introduce and address such matters (Lam et al. 2019).

Careful consideration should be given to resuscitation status, since this may be an issue during hospital admission. CPR in this group of patients may be inappropriate, depending on prognosis and comorbidity.

CARE OF PATIENTS MANAGED WITHOUT DIALYSIS

People who are being managed conservatively need much more than just symptom management (see Box 10.4). Achieving these goals requires a shift from a predominantly disease-focused approach towards more patient-centred

management (the disease itself, while it must not be neglected, is less important than overall quality of life, and patients should be encouraged to decide what treatment they can or cannot tolerate as the illness progresses). Careful judgements need to be made as to when to discontinue onerous treatments; these will often depend on perceived burden and patient preference.

SYMPTOMS TOWARDS THE END OF LIFE

Common physical symptoms that patients with CKD report are lack of energy or fatigue, itching (pruritus), pain, sleep disturbance, and restless legs (Fletcher et al. 2022) (see Box 10.5).

A number of studies report fatigue as extremely common (42–89%), (Artom et al. 2014). Pruritus has been studied extensively; some of the larger studies suggest that 40–70% of patients may be troubled by this symptom. Pain has been infrequently studied, but the few studies of it suggest that more than 50% of patients have pain (Fletcher et al. 2022)). Sleep disturbance and the related symptom of restless legs have been studied more often and appear to affect 30–52% of patients. Anxiety and depression may also be experienced by some patients. Patients who screen positive for depressive symptoms must be assessed to establish if their symptoms are related to depression or spiritual/existential concerns requiring ongoing support (Schell et al. 2023). A variety of other less common symptoms have been described, including anorexia, constipation, cough, dyspnoea, nausea, and vomiting. Most evidence comes from patients receiving dialysis; some symptoms (such as muscle cramps, pruritus, and restless legs) may be dialysis related, and will occur less often in conservatively managed patients, while other symptoms are disease related and will worsen with declining kidney function.

As the illness progresses, symptoms may worsen. For both people who are being conservatively managed and those withdrawing from dialysis, symptoms in the last days of life may follow different patterns. Unfortunately, there have been very few studies of symptoms in either group at the end of life. Cohen et al. (2000) carried out one of the few studies on dialysis withdrawal, and they describe pain, agitation, myoclonus (involuntary jerking of muscles), fatigue, and dyspnoea, each occurring in at least one in four patients in the last days of life.

SYMPTOM ASSESSMENT

The most important step is to identify symptoms when they are present. This is best done by asking the patient about potential or extant symptoms, in a systematic way;

BOX 10.4 MANAGING THE NEEDS OF PATIENTS CONSERVATIVELY

- Use skilled communication to facilitate the ‘not for dialysis’ decision, to explain disease progression and prognosis, and to facilitate future management decisions, in accordance with the patient’s information preferences.
- Regularly review the ‘not-for-dialysis’ decision.
- Continue disease management to maximise and maintain residual kidney function including medications that decelerate the progression of kidney disease and/or treat complications of ESKD.
- Conduct a psychological assessment to screen for depression and to discern whether the presented symptoms originate from depression or if they are linked to spiritual or existential concerns commonly experienced by individuals coping with advanced illness.
- Continue disease management to minimise symptoms.
- Make regular and detailed assessment of symptoms.
- Conduct proactive intervention to control symptoms.
- Do advance planning as the illness progresses, to:
 - avoid inappropriate acute admissions;
 - avoid inappropriate reversal of ‘not-for-dialysis’ decision;
 - enable place of care preferences to be met if possible.
- Conduct ongoing psychological and social care.
- Get involvement and support of family as appropriate.
- Attend to spiritual care, especially as the end of life approaches.
- Provide detailed and expert end-of-life care in the final days or weeks.

Source: Murtagh et al. 2016; Schell et al. 2023.

BOX 10.5**SYMPTOMS COMMONLY EXPERIENCED IN STAGE 5 CKD**

- Fatigue or lack of energy
- Itching (pruritus)
- Pain
- Psychological symptoms
- Sleep disturbance
- Restless legs
- Anxiety and/or depression
- Anorexia
- Constipation
- Cough and dyspnoea
- Nausea and vomiting

with an organised and sequential enquiry focusing on distinct areas such as cardiovascular, respiratory, and musculoskeletal systems. Symptom questionnaires such as the Patient Outcome Scale symptom module (renal version)

may be helpful and are freely available at Palliative care Outcome Scale (POS) – IPOS-Renal and Translations (POS 2012). Symptoms may go unrecognised in ESKD partly because the focus may have been on the disease itself and not the symptoms per se. Symptoms may also be related to other coexistent comorbidities, and not to the kidney disease, which may render systematic enquiry challenging. Many, if not most, of such patients will have several comorbid conditions and management of symptoms may fall to a variety of health professionals. However, these patients will have an eGFR of $<15 \text{ ml min}^{-1}$, and health professionals inexperienced in kidney care may have insufficient experience to confidently and effectively undertake relevant clinical management. The key to effective, high-quality symptom control is a multidisciplinary proactive, detailed, and thorough symptom assessment at regular intervals, to pre-empt patients reporting symptoms, or for new symptoms to emerge (Fitzgerald and Brown 2023).

Careful attention should be given to the underlying cause of each symptom. As an example, pain may be related to comorbid conditions than the kidney disease itself; with ischaemic pain from peripheral vascular disease, neuropathic pain from polyneuropathy (often related to diabetes mellitus), bony pain from osteoporosis, or musculoskeletal pain from a variety of causes, all typical common examples. Less often, there may be

specific discomfort related to the primary kidney disease, such as bone pain from kidney osteodystrophy (the dystrophic growth of bone caused by disturbances in the metabolism of calcium and phosphorus), cyst pain in polycystic kidney disease, or the infrequent but acute pain of calciphylaxis (the accumulation of calcium in small blood vessels within the skin, resulting in painful ulceration).

SYMPTOM MANAGEMENT

Management of symptoms in CKD is further complicated by the altered pharmacology of drug metabolism and excretion in advanced kidney impairment, with a potentially high risk of toxicity and side effects. The symptomatic presentation of such toxicity or adverse reactions may also be unclear because of comorbid conditions. A brief outline of the most frequent or challenging symptoms is given here, but more detail can be found elsewhere, such as Schell et al. (2023).

Fatigue or lack of energy

This is one of the commonest problems and can prove challenging to manage clinically. Interventions such as erythropoietin replacement and iron supplementation may be prescribed to maintain haemoglobin between 110 and 120 mg dl⁻¹ and may need to be continued even when prognosis is short, because of the symptomatic improvement they may provide. Nutritional advice and support under the guidance and input of a dietician should be carefully considered. Nonpharmaceutical measures can also be considered such as exercise, mindfulness and cognitive behavioural therapy. The evaluation of fatigue should include an assessment and management of anaemia and attention to underlying cardiovascular issues.

Additional potential factors that may contribute to fatigue include inadequate nutrition, insufficient fluid intake, a lack of vitamin D, irregular thyroid function, or the consumption of medications such as antiepileptics and antidepressants. It is also important to assess patients for sleep disturbances and psychological issues such as depression, anxiety, and existential distress.

To address fatigue via nonpharmacologic approaches, interventions should focus on enhancing nutrition and hydration, promoting gentle exercise within each patient's tolerance, optimizing sleep habits and patterns, fostering awareness and mindfulness, while identifying strategies for conserving energy (Schell et al., 2023).

Nausea and vomiting

It is important to try to identify the cause of such upset if effective management is to be achieved; the clinical history may be invaluable in this regard. Gastroparesis (reduced gastric motility, usually presenting with early fullness, bloating, vomiting after eating, and relief of nausea with vomiting) may respond to metoclopramide, which increases gastrointestinal transit time, at the risk of inducing uncomfortable spasm. Nausea as a direct result of high levels of toxic metabolites in the blood ('uraemic nausea') is typically more constant and less closely related to eating; haloperidol (a powerful centrally acting sedative antipsychotic agent) may prove effective although use and dosage may be limited by sedation. Other centrally acting antiemetic agents such as ondansetron may also be used, especially if nausea is drug-related. Persistent nausea or vomiting near the very end of life can be treated with levomepromazine a powerful receptor blocker.

A low dose of ondansetron, ranging from 4 to 8 mg every 8 hours as needed is recommended for ongoing nausea and vomiting. Alternatively, low-dose haloperidol at 0.5 mg every 8 hours as needed may also be effective. Metoclopramide, a dopamine antagonist, is particularly beneficial for conditions like gastroparesis and uraemia. When using metoclopramide, it is crucial to adjust the dosage based on the degree of kidney function impairment. It is important to avoid concurrently prescribing haloperidol and metoclopramide since both are dopamine antagonists. Vigilant monitoring for serious extrapyramidal reactions, presenting with distressing involuntary movements, is essential for patients using these agents, and adjustments in dosage or agent discontinuation may be necessary (Schell et al. 2023).

Pain

Pain management needs to be tailored, both to the individual patient and to the specific cause of the pain. If the cause cannot be removed or reduced, then pain medication should be given according to the World Health Organisation Analgesic Ladder (WHO n.d.). This consists of three steps:

- Step 1: a non-opioid, usually paracetamol; either orally or parenterally.
- Step 2: opioids for mild to moderate pain.
- Step 3: opioids for moderate to severe pain.

Initial analgesia should start with the lowest appropriate step. It is important to understand that if the full dose is insufficient for relief, then using another medication from the same 'step' does not usually provide any better relief and a move up to the next step of the therapeutic ladder is

indicated. Tramadol is an effective Step 2 opioid, although this drug should be used at a reduced dose and prolonged dose interval in stage 5 CKD (Broadbent et al. 2003). Use of Step 3 opioids in stage 5 CKD is highly problematic: morphine and diamorphine in particular tend to accumulate and readily cause toxicity. Fentanyl is a safer choice, although available formulations may prove restrictive (Murtagh et al. 2007b).

According to the cause of the pain, additional (adjuvant) medication may need to be used alongside opioids. This is particularly true of neuropathic pain, which may respond well to centrally acting agents such as gabapentin or pregabalin; being mindful of toxicity in patients with impaired kidney excretory capacity. Combination of these centrally acting agents with an opioid may prove particularly effective in pain control (Finnerup et al. 2015).

Dyspnoea

Shortness of breath (dyspnoea) can stem from various factors such as anxiety, anaemia, infection, metabolic acidosis, cardiac compromise and pulmonary oedema. In cases where volume overload plays a role, it is advisable to implement sodium and fluid restriction alongside diuretics, despite the potential risk of further compromising kidney function. Nonpharmacologic approaches to alleviate the sensation of breathlessness include sitting in an upright position, ensuring gentle airflow across the face, sustaining a humid environment, practicing pursed lip breathing, and considering supplemental oxygen (Schell et al. 2023). Pharmacological and non-pharmacological approaches to relieving anxiety can be rapidly effective.

Pruritus

Dry skin is very commonly associated with pruritus and should be actively managed with liberal regular emollients (such as aqueous cream). High serum levels of calcium, phosphate, magnesium, and parathyroid hormone have all been associated with pruritus to a greater or lesser extent (Lugon 2005), and these causes should be sought and actively managed. Oral antihistamines are often used, although there is little evidence for benefit, whilst topical antihistamines such as crotamiton may be equally, or additionally, effective, especially when sparingly combined with a topical steroid such as 1% hydrocortisone. If pruritus disturbs sleep, a sedative antihistamine (such as chlorpheniramine) given at night may be useful. Other treatment options include naltrexone (not with opioids), capsaicin cream (especially if pruritus is localised), or thalidomide (caution with handling).

Restless legs and sleep disturbance

These two symptoms frequently coexist. Simple measures, such as avoiding caffeine, avoiding alcohol in the evenings, and reducing daytime sleep, are important in facilitating sleep. Centrally acting hypnotic agents such as zolpidem, zopiclone, or temazepam can be used, although doses should be reduced in stage 5 CKD without dialysis, and the risk of dependence should be considered carefully in line with prognosis.

Restless legs can be managed specifically with reduction in caffeine (coffee, tea), theophylline (tea), and any aggravating medications (such as tricyclic antidepressant drugs). Active treatment of anaemia and low ferritin (which are both associated with restless legs) should be considered. Major tranquilisers such as clonazepam or dopaminergic agents may be prescribed, although these may be associated with re-emergent symptoms as tolerance develops, or with rebound symptoms after a dose reduction or withdrawal. For these reasons, the lowest possible doses should be used, and intermittent rather than continuous use may be helpful.

PSYCHOLOGICAL AND SOCIAL ISSUES

There are numerous psychological and social implications of living and dying with CKD, many of which are similar to other life-threatening or chronic diseases. The patient, together with their carer or family, faces various potential changes and these can be related to factors such as role change, appearance, sexuality, financial challenges, and becoming more physically dependent on others. It is important that timely discussions occur, to ensure that the patient and their family are prepared for and supported through potential changes as they are made aware of services and benefits that may be useful.

Psychological aspects of care are addressed more fully elsewhere (Schell et al. 2023), but failure to address psychosocial issues can lead to 'technical' treatment without healing. It is also important to provide support to the family caregivers; by doing this, the patient is additionally supported. The involvement of the multidisciplinary team is key to effective management in this important arena. The timely intervention of an occupational therapist can help promote independence and safety, which provides timely support for both patients and carers. Mindfulness techniques can help patients and carers reconnect with their bodies and experience life more fully. They encourage living in the present as opposed to dwelling on the past or worrying about the future and are endorsed by Kidney Care UK, the UK's support charity for people affected by kidney disease.

SPIRITUAL CARE

Palliative care considers the whole person, their family, and carers. It is important to consider all aspects and dimensions of each patient's existence, since psychological, social, and spiritual issues are important. For example, as Davison (2005) identifies, unless the psychological, social, and spiritual components of pain are addressed, pain may not be relieved adequately.

The term *spiritual* is ill defined and can mean very different things to different people and cultures. To add to the confusion, the terms *spiritual* and *religious* are frequently used interchangeably, which is semantically incorrect and may introduce confusion to an important area of care. Spirituality is to do with meaning, not necessarily through formal religious beliefs, while religion is an expression of spiritual beliefs through a more formal framework (Speck et al. 2004). Spiritual care should be integrated into practice to ensure that the whole person is represented and considered within the contexts of both their existence and their care. Illness, and the end of life in particular, involves mind and spirit, not just what happens to the body, and it is therefore important that care of all such domains is included in overall care.

Spirituality is often neglected until the end of life is perceived as being very near, leaving little time for spiritual care or resolution of important issues. The closeness of death, and the prospect of facing mortality, can have significant effects on both patient and family, as well as on healthcare professionals. Sometimes people look for meaning in what is happening, or ask the question 'why me?' There may be issues of guilt, or some families may be facing multiple losses or another recent bereavement. Knowledge and discussion of spiritual needs should help address these issues as death approaches, although attentive, active listening is frequently the most important skill in spiritual care.

The provision of access to a bereavement service is also important. Some kidney units offer an annual memorial service as part of their bereavement care. Families of patients who have died in the previous year are invited to the service, as well as kidney professionals. It is an opportunity for all to acknowledge the loss, to continue to provide support, and often helps families progress in their bereavement journey.

CONCLUSION

The needs of patients with kidney disease (and their families) as they become less well and as they approach the end of life, are complex. They require skilled and open communication from an early stage, advance planning, high-quality symptom control, and good psychological and spiritual care. Their families may also benefit from bereavement care. Effective delivery of such care also requires communication with, and coordination of, the network of professionals who may be involved, including primary care, kidney, and specialist palliative care professionals, as well as families and informal carers.

It is imperative that nephrology nurses develop generic palliative care skills to ensure that appropriate care, including good symptom relief, is given to patients and their families at all stages of their disease trajectory. In addition, partnerships with specialist palliative care providers need to be nurtured to ensure that their timely intervention can be of full benefit, and that there is maximum sharing of expertise and experience. The overall aim is to enable the last months and days of each patient's life to be lived as fully as possible, and for them to achieve a good death. It is a challenging area for nephrology nursing practice, but one that cannot and must not be ignored.

REFERENCES

- Artom, M., Moss-Morris, R., Caskey, F. et al. (2014). Fatigue in advanced kidney disease. *Kidney International* 86 (3): 497–505.
- Bansal, A.D. and Schell, J.O. (2018). A practical guide for the care of patients with end-stage renal disease near the end of life. In *Seminars in Dialysis* 31 (2): 170–176.
- Bello AK, Levin A, Lunney M, et al. (2019). Status of care for end stage kidney disease in countries and regions worldwide: international cross-sectional survey. *BMJ* 367: l5873.
- Bristowe, K., Selman, L., Higginson, I.J. and Murtagh, F. (2019). Invisible and intangible illness: a qualitative interview study of patients' experiences and understandings of conservatively managed end-stage kidney disease. *Annals of Palliative Medicine* 8 (2): 121–129.
- Broadbent, A., Khor, K., and Heaney, A. (2003). Palliation and chronic renal failure: opioid and other palliative medications – dosage guidelines. *Progress in Palliative Care* 11: 183–190.
- Byrne, C., Caskey, F., Castledine, C. et al. (2017). 19th annual report of the Renal Association. *Nephron Clinical Practice* 137 (suppl. 1): c1–c406.
- Charles, C., Gafni, A., & Whelan, T. (1999). Decision-making in the physician– patient encounter: revisiting the shared treatment decision making model. *Social Science Medicine* 49: 651–661
- Chen, J.O. and Chiu-Chu, L.I.N. (2021). Exploring the barriers faced by nephrology nurses in initiating patients with chronic kidney

- disease into advance care planning using focus-group interviews. *Journal of Nursing Research* 29 (6): e179.
- Chen, J.H., Lim, W.H. and Howson, P. (2022). Changing landscape of dialysis withdrawal in patients with kidney failure: Implications for clinical practice. *Nephrology* 27 (7): 551–565.
- Cohen, L.M., Germain, M., Poppel, D.M. et al. (2000). Dialysis discontinuation and palliative care. *American Journal of Kidney Diseases* 36: 140–144.
- Davison, S.N. (2005). Chronic pain in end-stage renal disease. *Advances in Chronic Kidney Disease* 12: 326–334.
- Davison, S.N., Levin, A., Moss, A.H. et al. (2015). Executive summary of the KDIGO Controversies Conference on supportive care in chronic kidney disease: developing a roadmap to improving quality care. *Kidney International* 88 (3): 447–459.
- Davison, S.N., Tupala, B., Wasylynnuk, B.A. et al. (2019). Recommendations for care of patients receiving conservative kidney management. *CJASN* 14 (4): 626–634.
- De Barbieri, I., Strini, V., Noble, H., et al. (2022). Nurse-perceived facilitators and barriers to palliative care in patients with kidney disease: A European Delphi survey. *Journal of Renal Care* 48 (1): 49–59.
- Department of Health (2011). *End-of-life Care Strategy, Third Annual Report*. London: Department of Health.
- Finnerup, N.B., Attal, N., Haroutounian, S., et al. (2015) Pharmacotherapy for neuropathic pain in adults: a systematic review and meta-analysis. *Lancet Neurol.* 14 (2): 162–173.
- FitzGerald, T.J. and Brown, E.A. (2023). Conservative kidney management. *Medicine* 51 (3).
- Fletcher, B.R., Damery, S., Aiyegbusi, O.L., et al. (2022). Symptom burden and health-related quality of life in chronic kidney disease: A global systematic review and meta-analysis. *PLoS Medicine* 19 (4): e1003954.
- García Testal, A., García Maset, R., Fornés Ferrer, V., et al. (2021). Cohort study with patients older than 80 years with stage 5 chronic kidney failure on haemodialysis vs conservative treatment: Survival outcomes and use of healthcare resources. *Therapeutic Apheresis and Dialysis* 25 (1): 24–32.
- Sala, I., Oliveira, J., Freitas, J., et al. (2021). MO815 beyond survival: comparison of haemodialysis and conservative management in elderly and frail stage 5 chronic kidney disease patients. *Nephrology Dialysis Transplantation* 36 (Supplement_1): gfab098-007.
- Jain, V., Sinha, S., Shaw, C., et al. (2023). Re-evaluating national screening for chronic kidney disease in the UK. *BMJ* 382.
- Lanini, I., Samoni, S., Husain-Syed, F., et al. (2022). Palliative care for patients with kidney disease. *Journal of Clinical Medicine* Jul 5; 11 (13): 3923.
- Lam, D.Y., Scherer, J.S., Brown, M., et al. (2019). A conceptual framework of palliative care across the continuum of advanced kidney disease. *Clinical Journal of the American Society of Nephrology* 14 (4): 635.
- Lugon, J.R. (2005). Uremic pruritus: a review. *Haemodialysis International* 9: 180–188.
- Mandel, E.I., Bernacki, R.E., and Block, S.D. (2017). Serious illness conversations in ESRD. *Clinical Journal for the American Society of Nephrology* 12 (5): 854–863.
- McPeake, M.L., Cook, N., McIlpatrick, S., and Hasson, F. (2023). The experience of shared decision-making for patients with end-stage kidney disease undergoing haemodialysis and their families—A scoping review. *Journal of Clinical Nursing* 32 (17–18): 6243–6253.
- Meghani, S. (2004). A concept analysis of palliative care in the United States. *Journal of Advanced Nursing* 46: 152–161.
- Mental Capacity Act (2005). <https://www.legislation.gov.uk/ukpga/2005/9/contents> (accessed 5 Jan 2024).
- Morton RL, Turner RM, Howard K, et al. (2012) Patients who plan for conservative care rather than dialysis: a national observational study in Australia. *American Journal of Kidney Diseases* 59: 419.
- Murtagh, F.E., Burns, A., Moranne, O. et al. (2016). Supportive care: comprehensive conservative care in end-stage kidney disease. *Clinical Journal of the American Society of Nephrology* 11 (10): 1909–1915.
- Murtagh, F.E., Chai, M.O., Donohoe, P. et al. (2007). The use of opioid analgesia in end-stage renal disease patients managed without dialysis: recommendations for practice. *Journal of Pain and Palliative Care Pharmacotherapy* 21: 5–16.
- National Kidney Federation (NKF) (2023). End of life care for renal patients <https://www.kidney.org.uk/end-of-life-care-for-renal-patients> (accessed 3 January 2024).
- National Institute of Health and Clinical Excellence. (2021). Shared decision making: a collaborative approach for all. <https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/niceguidelines/shared-decision-making#shared-decision-making-collaborative> (accessed 4 January 2024).
- NHS Kidney Care (2015). *End-of-life Care in Advanced Kidney Disease: A Framework for Implementation*. London: Department of Health.
- Noble, H., Brazil, K., Burns, A. et al. (2017). Clinician views of patient decisional conflict when deciding between dialysis and conservative management: qualitative findings from the Palliative Care in chronic Kidney diSease (PACKS) study. *Palliative Medicine* 31 (10): 921–931.
- O'Hare, A.M., Song, M-K., Kurella Tamura, M. et al. (2017a). Research priorities for palliative care for older adults with advanced chronic kidney disease. *Journal of Palliative Medicine*. 20 (5), <http://doi.org/10.1089/jpm.2016.0571>
- O'Hare, A.M., Szarka, J., McFarland et al. (2017b). “Maybe they don’t even know that I exist”: challenges faced by family members and friends of patients with advanced kidney disease. *Clinical Journal of the American Society of Nephrology* 12 (6): 930–938.
- Palliative care Outcome Scale (POS) (2012). IPOS – Renal and transplantations. <https://pos-pal.org/maix/ipos-renal-in-english.php> (accessed 1 December 2023).
- Public Health England (2014). Chronic kidney disease prevalence model. <https://tinyurl.com/y7ewnfdr>. (accessed 30th Sept 2023)
- Quinn, K.L., Shurrab, M., Gitau, K., et al. (2020). Association of receipt of palliative care interventions with health care use,

- quality of life, and symptom burden among adults with chronic noncancer illness: a systematic review and meta-analysis. *JAMA* 324 (14): 1439–1450.
- Renal Association. (2020). Commentary on the NICE guideline on Renal Replacement Therapy and Conservative Care. <https://renal.org/sites/renal.org/files/Commentary-on-the-NICE-Guideline-on-RRT-andconservative-management.pdf>.
- Saeed F, Sardar MA, Davison SN, et al. (2019). Patients' perspectives on dialysis decision-making and end-of-life care. *Clinical Journal of the American Society of Nephrology* 91 (5): 294–300.
- Schell, J., Arnold, R., and Davison, S. (2023). Kidney Palliative Care: Conservative Kidney Management. *Up to Date*. <https://www.uptodate.com/contents/kidney-palliative-care-conservative-kidney-management>. (accessed 1 October 2023)
- Shi, Y., Wang, L., Fangjian, D., et al. (2022). Factors promoting shared decision-making in renal replacement therapy for people with end-stage kidney disease: Systematic review and qualitative meta-synthesis. *International Urology and Nephrology* 5 (4): 533–574.
- Song, Y.H.; Cai, G.Y.; Xiao, Y.F.; Chen, X.M. (2020). Risk factors for mortality in elderly haemodialysis patients: A systematic review and meta-analysis. *BMC Nephrology* 21: 1–10.
- Speck, P., Higginson, I., and Addington-Hall, J. (2004). Spiritual needs in health care. *British Medical Journal* 329: 123–124.
- Tavares, A.P.D.S., Santos, C.G.D.S., Tzanno-Martins, C., et al. (2020). Kidney supportive care: an update of the current state of the art of palliative care in CKD patients. *Brazilian Journal of Nephrology* 43: 74–87.
- Thaminda, L. et al. (2015). Worldwide access to treatment for end-stage kidney disease: a systematic review. *The Lancet* 385 (9981): 1975–1982.
- UK Renal Registry (2023). UK Kidney Association 25th Annual Report – data to 31/12/2021, Bristol, UK. <https://ukkidney.org/audit-research/annual-report> (accessed 4 January 2024).
- World Health Organisation (2020). Palliative Care, <https://www.who.int/news-room/fact-sheets/detail/palliative-care> (accessed 30 September 2023).
- World Health Organization (WHO) (n.d.). World Health Organization Analgesic Ladder https://professionals.wrha.mb.ca/old/professionals/files/PDTip_AnalgesicLadder.pdf (accessed 1 December 2023).

Kidney Care in Infancy, Childhood, and Early Adulthood

Diane Blyton and Shelley Jepson

Nottingham Children's Hospital, Nottingham, UK

LEARNING OUTCOMES

- to gain an understanding of the physiological differences between children and adults.
- to develop an appreciation of the psychosocial impact of chronic kidney disease (CKD) and renal replacement therapies on children and their families.
- to identify the key differences in the management of CKD, dialysis, transplantation, and acute kidney failure in children.
- to be able to identify important issues around transition, and the transfer of young people to adult services.

INTRODUCTION

The aim of this chapter is to address the unique needs of infants, children, and young adults who have kidney damage. The challenge is to meet the needs of the patients and their parents within each of these age groups.

Infants and young children are dependent upon their parent/carer for their global needs, and as they mature, they are increasingly able to become self-caring. The NHS England service specification for paediatric nephrology services (NHS Commissioning Board [now known as NHS England] 2013) recognises that children and young people with renal disease require care from full multidisciplinary teams to ensure support for their physical, psychosocial, and emotional needs. The approach taken with this client group needs to be flexible, and the multiprofessional team needs to be diverse to support this. Specialist units will commonly comprise not only medical staff and specialist nurses but also specialist dietitians, social workers, hospital play specialists, hospital school teachers, psychologists, pharmacists, and youth workers.

Kidney disease in childhood is rare and in the United Kingdom care is delivered in only 13 tertiary centres.

Wherever possible, efforts are made to treat children as close to home as possible, and a network model of care is encouraged (BAPN 2008).

Key concerns are the psychosocial impact of a condition, which will often be long-term, on both the child and their family (Department of Health 2006a). A recent study has reported poorer overall quality of life, and poorer physical, school, emotional, and social functioning, in children with mild-to-moderate CKD compared with healthy children (Gerson et al. 2010). The prevention of complications that may have an impact on the health of the child throughout their future, on transfer to adult services, is also important.

The following sections will highlight both the physiological and psychosocial differences between children and adults, and how renal replacement therapies need to be adapted accordingly.

PHYSIOLOGY IN CHILDHOOD – IMPACT ON RENAL CARE

There are several key areas where physiology in childhood differs from adulthood.

GROWTH

Children should be continually growing, with accelerated growth spurts during infancy and adolescence. The 50th percentile birth weight is 3.3–3.5 kg and during infancy growth is 60–240 g/week, gradually declining to 2 kg/ year during childhood. Growth accelerates during infancy and puberty (Shaw and McCarthy 2020).

Several factors affect growth, including diet, genetic inheritance, and growth hormone production, which are discussed further below.

FLUID BALANCE

Seventy-five percent of the body is comprised of water in newborn infants, decreasing to 45% in young adults. There is also a greater proportion of extracellular water in infants; therefore, water is more easily lost, particularly during pyrexia (Mondozi et al. 2015).

RENAL ANATOMY

Neonates' kidneys are affected by the removal of blood flow from the placenta, leading to a reduction in glomerular filtration rate (GFR) and renal blood flow.

At birth the kidneys have the correct number of nephrons, but they are immature. Newborns have small, underdeveloped glomeruli, short loops of Henle, and an underdeveloped renal cortex.

There is a reduced ability to concentrate urine, and also to secrete hydrogen ions. This becomes particularly important if the infant enters into a state of metabolic acidosis.

GFR does not reach close to adult values until a child reaches 1–2 years of age (Ring and Camille 2015).

Careful consideration is needed when monitoring children and ensuring that age-appropriate parameters are used. Age-appropriate reference ranges should be consulted for biochemistry results throughout childhood (see Table 11.1).

Blood pressure increases with size/age. Height centile charts should be used to monitor blood pressure in children with short stature for accuracy. Cheung et al. (2021) recommend aiming for a systolic blood pressure of <90th percentile for age, sex, and height.

CHRONIC KIDNEY DISEASE

The common causes of CKD in children are different from those experienced in later life, as indicated in Table 11.2. In comparison to the adult population, it is difficult to gain accurate figures. In 2020, data suggested that the incidence of end-stage kidney disease was 63.8 pmarp (per million age-related population) (UK Renal Registry 2022).

Table 11.1 Biochemistry reference ranges for children.

Sodium (mmol l ⁻¹)		132–142
Potassium (mmol l ⁻¹)	<1 month	3.0–6.6
	>1 month	3.0–5.6
Bicarbonate (mmol l ⁻¹)		22–32
Urea (mmol l ⁻¹)		2.5–6.5
Albumin (g l ⁻¹)		34–45
Calcium (mmol l ⁻¹)	<1 year	2.4–2.8
	1–2 years	2.3–2.7
	3–16 years	2.2–2.6
	Adult	2.2–2.6
Phosphate (mmol l ⁻¹)	<4 weeks	1.2–3.1
	5 weeks–6 months	1.5–2.4
	6 months–1 year	1.5–2.1
	1–3 years	1.2–2.0
	3–6 years	1.0–1.8
	6–15 years	1.0–1.7
Creatinine (μmol l ⁻¹)	Adult	0.8–1.4
	<5 years	<44
	5–6 years	<53
	6–7 years	<62
	7–8 years	<71
	8–9 years	<80

Table 11.2 Common causes of ESKD in children.

Tubulointerstitial disease	46.8%
Glomerular disease	18.7%
Familial/hereditary diseases	15.1%
Systemic diseases affecting the kidney	4.8%
Other	14.5%

Source: UK Renal Register 2022.

The presenting symptoms of CKD commonly seen in children are shown in Box 11.1.

Children can present at any age and at different stages of renal disease. It is important that investigations are undertaken to determine cause and therefore the interventions required. Dialysis may be necessary in some cases; however, many children can be treated conservatively.

Some conditions are familial and therefore siblings may also need to be assessed, even if they are asymptomatic. In rare cases a parent and one or more children may be

BOX 11.1**PRESENTING SYMPTOMS
OF CKD IN CHILDREN**

- Failure to thrive or anorexia
- Nausea, vomiting, and loss of appetite
- Lethargy
- Headaches and high blood pressure
- Reduced urine output or polyuria/polydipsia, possibly wetting

dialysis dependent, and a thorough plan of psychosocial support is a necessity in this situation.

CONSERVATIVE MANAGEMENT

Providing the biochemistry is stable, children can be maintained without dialysis for some time. This applies for children with both CKD and acute kidney injury (AKI). Several interventions can be incorporated into conservative management. These interventions continue into the established phase of CKD, and may be temporarily used to support children in an acute phase of renal disease.

Diet (also see Chapter 12)

Children with renal disease experience problems with growth, electrolyte management, mineral bone disease, anaemia, and hypertension.

It is important that a paediatric renal dietitian is involved in the management of children with renal disorders (NICE 2021). Dietary control can assist in delaying the need for dialysis and all of the medical and psychosocial problems associated with it. Adequate nutrition is also important for growth and neurological development.

Energy requirements should be based on EAR (estimated average requirement) for chronological age, or height age if the child falls below the second percentile (Royle 2015).

Individualised dietary guidance is needed for each family, based on the child's biochemistry, stage of CKD, and renal replacement therapy used. Negotiation with food allowances is often needed with older children to improve adherence to the nutritional plan. Clear education is needed for the child and their parents to ensure understanding of the necessity to restrict many of the favourite childhood foods, such as chips and pizza. Sodium, potassium, and phosphate intakes often need to be altered. Patients with renal tubular disorders, such as Bartter syndrome, are at risk of electrolyte and fluid imbalances

(Ring and Camille 2015). Supplements are often required. Protein intake may also need to be modified to balance growth requirements against potential uraemia.

High-energy food and drinks are encouraged, as it can be difficult to achieve EAR when on an altered diet.

It is common for younger children, and infants in particular, to refuse to eat, and enteral feeding via the nasogastric or gastrostomy route is often required. Gastrostomy feeding in particular has been shown to be a valuable tool in nutritional support (Rees et al. 2021).

Socialisation with food is still important, with the end goal of transplantation in mind. Feeding problems can remain in a small number of children following a successful transplant and speech and language therapy can be required, to promote progression to an age appropriate diet as children may need to relearn how to eat (Rees et al. 2021). Conversely, in older children advice is often needed to prevent excessive weight gain, particularly when taking corticosteroids as immunosuppression.

Fluid management

The approach to fluid management will depend on whether the child concerned has a reduced urine output or is polyuric.

Patients who have a reduced urine output will usually be given a fluid allowance, and also be prescribed a diuretic regimen. The common guideline used is to add 400 ml m⁻² surface area/day to the average daily urine output, to allow for insensible losses (Royle 2015). Some children are polyuric, and great care needs to be taken to ensure that fluid intake is sufficient to prevent dehydration.

Along with dietary changes, it is the reduction in fluid allowance that older children often find the most difficult to adhere to. It is important to provide an individualized plan for fluid management in conjunction with dietary advice (Ashby et al. 2019). Fluid overload is a contributor to hypertension in many patients, and therefore can affect cardiovascular health.

BLOOD PRESSURE

As with adults, hypertension is a complication that children with renal disease may experience. It is essential that accurate measurements are taken, to enable effective treatment of hypertension. Cardiovascular complications are a major cause of mortality and morbidity in adult patients. Slowing the progression of CKD, avoiding long-term dialysis, and, if possible, conducting pre-emptive transplantation may represent the best strategies to decrease the risk of premature cardiac disease (Weaver and Mitsniefes 2018).

Prevention of early complications is therefore essential, with hypertension being one of the most modifiable. Hypertension has also been associated with acceleration of renal disease and there is evidence that intensified blood-pressure control, with target 24-hour blood-pressure levels in the low range of normal, confers a substantial benefit in terms of slowing kidney disease progression (ESCAPE trial group et al. 2009).

Blood pressure increases with age, and there are reference guidelines to assist in patient management. As children with renal insufficiency are often short in stature their height should be used as a reference, rather than chronological age. Target blood pressure should be less than the 90th percentile due to risk of organ damage (Sinha et al. 2019). There are charts based on gender, age, and height which should be used (Lurbe et al. 2016).

The British Hypertension Society has guidelines on blood pressure measurement, which include some guidance on children (<http://www.bhsoc.org>). Blood pressure measurement in children can be difficult to obtain. There are a limited number of oscillometric devices that are validated for use in children. Abnormal readings should be confirmed by completing a manual blood pressure measurement, before treatment is commenced (Lurbe et al. 2016). See Box 11.2 for a summary of blood pressure measurement guidelines.

Very small children can be uncooperative, and it is usually difficult to hear Korotkoff sounds in small children using a stethoscope. As a result, Doppler devices are recommended in children under 2 years of age. Single readings should not be used to direct management because white-coat hypertension can be particularly problematic in children. Ambulatory blood pressure monitoring is often used to assist in correct treatment of hypertension, enabling monitoring away from the hospital environment (Krmr 2018).

BOX 11.2

KEY PRINCIPLES IN BLOOD PRESSURE MEASUREMENT

The bladder in the cuff should cover 80–100% of arm circumference. Doppler devices are the recommended method in children under 2 years. Inflate to 30 mmHg above the estimated systolic pressure.

Deflate the cuff at 2–3 mmHg s⁻¹.

Record the reading to the nearest 2 mmHg.

Blood pressure should be compared to centile charts for height, age, and gender.

ANAEMIA

Anaemia is also associated with an increased risk of cardiac morbidity and mortality, and it affects growth and development. Haemoglobin should be maintained between 95 and 115 g l⁻¹ in the under twos and 100–120 g l⁻¹ in older children (NICE 2021). Initially, oral iron supplementation with nutritional management is sufficient in managing anaemia. However, as renal function deteriorates (usually GFR < 60 ml⁻¹min⁻¹ 1.73 m⁻²) erythropoietin stimulating agents may need to be introduced. Most children with established kidney disease require treatment.

Intravenous iron is usually given on an as-required basis; however, weekly doses for children on haemodialysis can be effective in counteracting the blood loss experienced. Whenever possible, blood transfusions are to be avoided.

GROWTH AND BONE HEALTH

Growth in chronic disease is multifactorial, including age of onset and effect of gastrointestinal reflux. The involvement of a specialist dietician is essential to maximise diet and therefore growth potential (Qizlebash, Cleghorn, and McAlister 2020).

Renal bone disease is a major contributor to growth problems. Close monitoring of phosphate levels and parathyroid hormone is essential. Dietary modification should begin when abnormal results are seen (NICE 2021). Vitamin D analogues should be introduced when serum levels fall below recommended levels, and must be monitored. Changes to dose/type may be needed if parathyroid levels become affected (Santos et al. 2021).

Phosphate-binding medication is often required, with calcium-based binders recommended as a first line when children reach CKD stage 4–5 (NICE 2021). In infants and young children this is added as a suspension into feeds, whereas older children follow similar regimes to adults. Adherence can be a problem, and education and negotiation are essential to identify a regime that is realistic for the young person.

The 24th UK Renal Registry report (2022) suggests that only 13.6% of children and young people under 16 years of age on dialysis achieved below-target level for phosphate, reflecting the challenges in preventing complications.

The complications of hyperparathyroidism, including the impact on growth are well known. Progression to tertiary hyperparathyroidism can make long-term treatment very difficult, and historically may have led to

the need for a parathyroidectomy. Calcimimetic drugs are being researched in the paediatric population to review the effectiveness of their use, following positive results in the adult population.

Growth problems in children with renal disorders have been associated with deranged secretion of growth hormone and resistance, particularly during periods of metabolic acidosis. Recombinant growth hormone can be effective, and this treatment should be considered once nutritional status is optimised (Qizlebash, Cleghorn, and McAlister 2020).

NEPHROTIC SYNDROME

Nephrotic syndrome is the most common glomerular disease in childhood with an incidence of 1.15–16.9 per 100,000 children per year globally (Trautman et al. 2022) and around 2.3 per 100,000 in the UK increasing to 9–16 per 100,000 in children of South Asian ethnic origin (Norman and Christian 2022).

Nephrotic syndrome is characterised by a triad of symptoms: proteinuria (early morning protein to creatinine ratio greater than 200 mg mmol⁻¹), hypoalbuminaemia (plasma albumin less than 25 g l⁻¹), and generalised oedema (Lennon et al. 2009). Oedema develops when a loss of plasma protein leads to a fall in oncotic pressure and water leaks into the interstitial space. Elevated plasma cholesterol frequently occurs.

Commonly, primary nephrotic syndrome arises from idiopathic causes. Secondary causes of nephrotic syndrome can be infection, allergic disorders, or systemic disease such as Henoch–Schönlein purpura. For paediatric patients, 85–90% respond well to corticosteroid therapy and will achieve remission (Trautmann et al. 2022). These patients are classed as having steroid sensitive nephrotic syndrome (SSNS).

The standard treatment of SSNS is with prednisolone, 60 mg/m² daily for 4 weeks followed by 40 mg m⁻² day⁻¹ on alternate days for a further 28 days. The child is considered to be in remission when the urine has been negative of protein for three consecutive days. Relapse occurs when there is proteinuria of 3+ or more on dipstick for three consecutive days after remission (Krishnan 2012). Relapse occurs in approximately 80% of children, requiring high-dose steroid treatment until remission, followed by 40 mg/m² steroid alternate days for 4 weeks (Norman and Christian 2022). Tapering of the steroid dose is no longer recommended. The use of high-dose steroids for prolonged durations can have serious side effects, including weight gain, mood swings, hypertension, and increased blood sugar. Alternative therapies are now routinely considered, and Rituximab is

commissioned for the treatment of relapsing SSNS (NHS England 2015).

Renal biopsy is only indicated if remission is not achieved within 28 days of commencing treatment.

NURSING CARE OF CHILDREN WITH NEPHROTIC SYNDROME

Accurate monitoring of fluid balance is essential along with daily weight and regular blood pressure measurement. Frequent assessment of oedema is necessary, and mobilisation should be encouraged to disperse oedema. Oedema can be especially debilitating to infants and children due to their greater volume of interstitial and total body fluid volume (Lee 2021). Use of a tool to assess the risk of pressure ulcers in paediatrics is recommended (Smith et al. 2019).

Although oedema may be present, hypovolaemia may occur due to the shift of fluid into the interstitial space. Aggressive use of diuretics can result in acute kidney injury (Lee 2021) and should therefore be used with extreme caution. Daily monitoring of serum electrolytes is necessary. In severe cases of oedema or hypovolaemia, 20% albumin infusions may be prescribed. Albumin should be administered with caution and frequent observations made during and after the infusion. Furosemide given part way through an/or at the end of the infusion is recommended if the child appears well filled (Norman and Christian 2022).

Urine should be checked for protein daily, and a teaching programme should be arranged for children and carers, so that they can continue with urinalysis following discharge. Advice about steroid dosage and potential side effects should be given. Referral to a paediatric renal dietitian is recommended. A healthy eating plan should be observed with a no-added-salt diet. Monosaturated or polyunsaturated fats should be used to prevent hyperlipidaemia. Caring for a child with nephrotic syndrome can present a large burden of care to parents and carers. Signposting to support networks is recommended (Nephrotic Syndrome Trust 2023).

In cases of frequent relapse or steroid dependence, second-line nonsteroidal treatment is necessary. These children should be referred to a paediatric nephrologist and treatment such as Levamisole, cyclophosphamide, tacrolimus, or Rituximab should be considered. In tertiary renal centres, nurses specializing in nephrotic syndrome may be employed to support families with treatment, care, advice, and follow-up. Minimal change nephrotic syndrome has a favourable prognosis. Most children will outgrow the disease in their teenage years (Norman and

Christian 2022). Follow-up for 5 years following the last relapse is recommended.

CONGENITAL NEPHROTIC SYNDROME (CNS)

This is a rare, inherited disorder, which presents in utero or during the first 3 months of life (Boyer et al. 2020). It is characterised by heavy proteinuria, oedema, and hypoalbuminaemia. Unlike childhood nephrotic syndrome, the disease cannot be controlled with the use of steroids. Most children with CNS will require dialysis by 2 years of age (Dufek et al. 2018). The complications of dialysis in small children are discussed later in this chapter.

The management and nursing care of children with congenital nephrotic syndrome can be extremely challenging, and referral to a paediatric nephrology centre is crucial. Previously, daily albumin infusions were recommended, along with consideration of nephrectomy and renal replacement therapy. More recent consensus suggests a conservative management approach optimizing nutrition and complication prophylaxis (Boyer and Berody 2022).

Parents and carers of infants with CNS need the support of a multidisciplinary team. A shared decision-making approach regarding treatment or palliative care is recommended (Boyer et al. 2020). A parallel planning approach to palliative care is helpful to acknowledge the uncertainty of the child's diagnosis (Wolff 2021). This involves meeting members of the palliative care team to prepare for the possibility of end of life, while staying under the care of the nephrology centre.

RENAL REPLACEMENT THERAPY

TRANSPLANTATION

Transplantation is the treatment of choice for children with ESKD. In 2020, 76.2% of children with ESKD were transplanted and 32.8% of children with established renal disease were reported to have been pre-emptively transplanted over a 5-year period (UK Renal Registry 2022). Normal renal function provides children with better opportunities for growth and development. In addition, successful transplantation maximises the amount of education and normal childhood activities, which may be compromised during dialysis.

It is possible to transplant kidneys from adult donors depending on the size of the child's abdominal cavity. If the donor kidney is disproportionately large, it may be placed intraperitoneally. However, the extraperitoneal position is preferable, as this preserves the peritoneum for dialysis and avoids long-term complications.

Transplantation into very small children is rarely successful. Most transplant surgeons require children to weigh approximately 10 kg or have reached at least 22 months of age before transplantation is considered. This is due to the risk of infarction in small vessels postoperatively (Oomen et al. 2022). Children receiving renal replacement therapy from birth therefore require the maintenance of dialysis access up until this time. This places a significant burden on the carers and a challenge for professionals.

LIVING DONOR TRANSPLANTATION

Because the 2019 Kidney Offering Scheme no longer prioritises children and young people, paediatric access to deceased donors has declined. The median wait for a deceased donor kidney for a paediatric recipient has increased to 270 days (NHS 2022), so living donor transplantation is now routinely considered as an early option. In children, the donor is most frequently a parent, although donation from grandparents has been reported. UK law prohibits minors from donating a kidney and therefore siblings under 18 years are not considered. For children placed on the deceased donor waiting list, the avoidance of parental antigens will allow living related transplantation to be considered in the future.

Living related donation (LRD) is advantageous in that families are able to plan the timing of the transplant, which allows them to consider employment, education, and family arrangements. It is recommended that children receiving kidney transplants be cared for within a specialist paediatric nephrology unit (NHS England 2023); therefore, there is the potential for the recipient and the donor to have surgery at different hospitals simultaneously. Professionals need to pay attention to the psychosocial needs of the family during this time, as often there is geographical separation between the donor, recipient, and carers. Supportive care could be provided in terms of webcam technology (Renal Association 2018).

PRE-EMPTIVE TRANSPLANTATION

Transplantation prior to the need for dialysis is considered to be the gold standard for treatment of ESKD and was reported to be achieved in 32.8% of children over a 5 year period (UK Renal Registry 2022). The benefits of transplant before dialysis include: less interruption of schooling and family life, preservation of the peritoneum and vessels for future dialysis treatments, improved growth and

development, and reduction in the symptoms of established renal failure.

A child is generally considered for transplantation once the GFR has fallen below $10\text{--}15\text{ ml min}^{-1} 1.73\text{ m}^{-2}$ and dialysis is anticipated within 12–24 months and/or a significant complication of growth failure is present. In addition, pre-emptive transplantation should be considered if the child exhibits symptoms of ESKD, i.e. renal bone disease, poor growth, fatigue, and inability to take part in normal childhood activities.

CARE OF THE CHILD AFTER KIDNEY TRANSPLANTATION

Nursing care of the child following renal transplant must be in a designated high-dependency nursing area in order to ensure close monitoring. Postoperative complications include bleeding, vascular thrombosis, and delayed graft function (Williams 2012). After the first 48 hours, recovery is generally fast and, if there are no complications, children can be discharged 7–10 days following transplant.

Careful attention to kidney function and immunosuppression levels is necessary, and children are usually seen as an outpatient several times a week in the first 4 weeks. Due to the long travelling distances to the specialist centre for paediatric patients, close collaboration with local health centres and district hospitals is encouraged so that blood tests can be taken locally and results sent to the tertiary centre. The donor is nursed in the adult unit, which may be in a different hospital. Follow-up is at the donor centre. Families are encouraged to engage with extended family support networks to ensure support of the donor as well as the child.

IMMUNOSUPPRESSION

There is currently no standard immunosuppression regimen for children and young people undergoing renal transplantation. However NICE guidance (2017) recommends Basiliximab, Tacrolimus, Mycophenolate Mofetil, and rabbit anti-human thymocyte immunoglobulin as initial options to prevent organ rejection in children and young people. There are newer immunosuppressant agents targeting different sites in immune activation pathways, such as Sirolimus and Everolimus.

The paediatric population, specifically adolescents experience the worst rates of graft loss and lack of adherence to immunosuppression is recognized as a major contributory factor (Corr et al. 2023). Education programmes which cater for young peoples' individual needs are recommended (Corr et al. 2023).

COMPLICATIONS

There are several potential complications following paediatric renal transplant. Hypertension is recognised as an important risk factor for cardiovascular morbidity and graft survival in transplanted children, with post-transplant hypertension occurring in 40–80% of transplanted children (Mohammed and Kapur 2023). Causes include immunosuppression therapy, graft dysfunction, stenosis, and weight gain. Ideally, hypertension should be confirmed using 24-hour automated blood pressure monitoring. The systolic blood pressure should be maintained at $< 90^{\text{th}}$ percentile for age, gender, and height ($+1.28\text{SD} = 90^{\text{th}}$ percentile) or $130/-\text{ mmHg}$, whichever is lower.

Other complications include urinary-tract infection, rejection, and recurrence of primary disease. Regular follow-up and 24-hour access to the nephrology centre is essential.

PREPARATION FOR DIALYSIS AND TRANSPLANT

Prior to commencing renal replacement therapy, children, young people, and their carers need to be given information regarding treatment options. In order for them to make an informed choice, information that is appropriate to age and understanding must be available. Hospital play specialists, trained to prepare children for procedures, are invaluable members of the paediatric multiprofessional team. Evidence shows that appropriate preparation for family members prior to treatment may prevent trauma later (Agerskov et al. 2021). Preparation and information are important for patients with CKD in advance of requiring a transplant or dialysis (NICE 2018). Consideration must also be given to siblings who may feel distressed by the treatment and are concerned about family separation (Batte et al. 2006).

There are a number of investigations that are required within the preparation period. These are summarised in Box 11.3.

IMMUNISATION

Live vaccines should not be given in children who are immunosuppressed. In order to receive optimal protection against infectious diseases children should be given a full course of primary immunisations prior to transplant listing. In addition to routine childhood immunisation, hepatitis B, BCG, pneumococcus, inactivated influenza and varicella zoster vaccine should be given to nonimmune children.

BOX 11.3**INVESTIGATIONS REQUIRED
PRIOR TO RENAL
REPLACEMENT THERAPY**

Blood group
Tissue type
Cytotoxic antibodies
Parental cross-match (if requested)
Immunisations
24-hour urine collection
ECG
Urological opinion
Urodynamics, if indicated

DIALYSIS

Pre-emptive transplantation is often the goal, but it may not be possible. Peritoneal dialysis (PD) is often the dialysis of choice if a transplant is not available, however, some families may choose haemodialysis, or PD may not be a suitable choice physically or psychosocially. It is important that children and their families are aware of all of the options available and that they are actively involved in the decision-making process (NICE 2018).

Other professionals also require information when children progress onto dialysis. General practitioners and community health staff should be informed of changes in the child's treatment.

School and nursery visits are also often required to provide training and support to teachers and other carers who may be responsible for the child (NHS England 2013).

PERITONEAL DIALYSIS

One benefit of PD in paediatric patients is the reduced disruption to normal life. It is the recommended therapy in children under the age of two (National Institute for Health and Care Excellence 2018). In many paediatric units, automated PD is the most frequent mode of delivery. In the data collected in 2020, 86% of children under 2 were on PD. This reduced to 12% as an overall in all patients under 12 (Renal Registry 2022). This is usually carried out overnight, reducing the impact on schooling in particular. Machines can deliver fill volumes as low of 60 ml with reduced recirculation of fluid using specialised sets, therefore enabling most infants to be dialysed this way. Infants requiring lower volumes are usually hospitalised following transfer from Neonatal Services.

Dialysis in infants can be technically challenging with risk of infection, higher incidence of gastrointestinal reflux, and other co-morbidities (Madden et al. 2020).

Fill volumes are usually calculated based on surface area (600–800 in children under 2, 1.0–1.2 l m⁻² in older children) (National Kidney Foundation 2006).

Ambulatory PD is less frequently used for younger patients as they are typically high transporters and therefore shorter cycles used with CAPD are more effective. Young adults may choose CAPD, as it gives them more freedom during the evenings and it is estimated that less than 30% of paediatric patients use this mode of PD.

The PD fluid prescription for children and the type of fluid and dwell time is determined on an individual basis depending on size and tolerance, residual renal function, growth, and other co-morbidities (Madden et al. 2020).

- Parental/carer burnout is always an issue (Oveyssi et al. 2021). Whenever possible, young adults are taught to undertake their own dialysis, with the support of another family member. However, with young patients there is a reliance on their relatives to provide this treatment. Where possible, respite care provision should be made available.

Infection is a major concern in the paediatric population. Peritonitis can quickly lead to systemic illness in very young children. There is also the long-term treatment of the child/young person to consider, and they may sometimes face a return to dialysis at a later date. Therefore, it is very important to prevent sclerosis of the peritoneum due to either repeated or single severe peritonitis episodes, increasing the longevity of this type of dialysis. Changes in treatment modality may be required if a child has repeated peritonitis episodes. Periodic updating of families on technique should be considered as this may reduce the risk of infections and other complications from practices at home; however, this is an under-researched area.

HAEMODIALYSIS

Haemodialysis is often the second choice of dialysis in children. This is due to the frequency it can be offered and the impact on the child and family. It is recommended that children should be cared for in a specialist paediatric renal unit. However, because of the very small numbers of children requiring this treatment, there are only 13 paediatric renal units in the UK. This inevitably leads to children travelling to receive this treatment. As a result, the psychosocial and economic impact of haemodialysis can be considerable for children and their families (Rees et al. 2017).

School provision is important for older children. Young adults who dialyse three to four times a week are

unable to attend school with their peers on dialysis days. Preschool children need distraction as well as play programmes to promote their global development.

Families need support, particularly those with children under 16, who must be transported with an escort each time they attend the hospital.

VASCULAR ACCESS

Central lines are frequently used as a form of chronic access, particularly in children awaiting transplantation for which dialysis will hopefully be a relatively short-term treatment. A range of sizes is required for the patient group cared for in paediatric renal units.

There is a risk of occlusion and infection, as with any central venous access device. Complications are carefully monitored.

Arteriovenous fistulae are used, more for older patients with a longer-term need for dialysis. Use in younger patients is limited by vessel size and nursing expertise. The Fistula First, Catheter Last approach is increasingly being considered in paediatric units due to reported reduction in complications when using AV fistulas (Preka et al. 2021).

The challenge in children is maintaining access sites for the future, which can become very problematic in children receiving kidney replacement therapies from a very early age. Consideration in paediatric units needs to be given to saving vessels and being careful in approaches to venepuncture to address this.

PRESCRIBING DIALYSIS AND ADEQUACY

Standardised treatment regimens cannot be used in patients on paediatric programmes. Guidelines on prescribing haemodialysis safely must be adhered to, to ensure adequate dialysis whilst preventing complications of over-efficient dialysis such as disequilibrium. Common guidelines are a pump speed of 5–7 ml⁻¹min⁻¹kg⁻¹ (Ashby et al. 2019). It is also important to use a circuit less than a maximum of 10% of the child’s total circulating volume (see Box 11.4). A variety of line volumes and dialysers must be available to meet these requirements.

Where this is not possible it can be necessary to prime the dialysis circuit with albumin or blood. If blood is used repeatedly, the same donor should be requested to reduce the sensitisation risk for future transplantation (Kaur and Davenport 2014).

First treatments should use a dialyser with a surface area no more than 75% of the child’s own surface area to monitor the effects of the treatment, particularly in patients with elevated ureas. This is usually increased in size up to

BOX 11.4

BLOOD VOLUME CALCULATION

Neonates	90 ml kg ⁻¹
Infants and children	80 ml kg ⁻¹
Adults	65 ml kg ⁻¹

Source: Willock and Jewkes (2000).

the child’s surface area to achieve a urea reduction rate (URR) of at least 65%. An equilibrated K_t/V of > 1.2 for children on three times a week treatment is recommended by the Renal Association (2019).

Careful consideration is also needed in guiding fluid removal on dialysis. However, there is a lack of guidance on exactly how to approach this, such that most paediatric dialysis units have developed their own protocols. Often, these incorporate a maximum of 5% reduction in fluid volume in a session. Blood volume monitoring and bioimpedance can be used to guide fluid removal and can be a useful tool in assessing dry weight. Due to the continual growth of children regular reviews are required to prevent frequent hypotensive episodes during dialysis, which has been reported to be 9–30% of haemodialysis sessions (Snauwaert et al. 2022).

It is difficult to identify whether it is haemodiafiltration (HDF) or high flux haemodialysis with ultrapure water in the paediatric population that is responsible for the cardiovascular benefits seen in the 3H study. However, in this study the safety in delivering HDF has led to many units being confident in its use in children and young adult patients (de Zan et al. 2022).

HOME HAEMODIALYSIS

Home haemodialysis in children and young people has increased in recent years, with many units now offering this alongside incentre haemodialysis for children and young people. Most patients have treatment 3–4 times a week, but can fit their treatments around their lifestyle. Initial training takes approximately 6 weeks, and assessment of the family circumstances needs to be considered to ensure this is commenced (Hothi et al. 2016).

ACUTE KIDNEY INJURY

AKI is characterised by a reversible increase in plasma creatinine and urea and by the inability of the kidney to regulate fluid and electrolyte balance.

The management of AKI in children has improved with advances in treatment for infants and children. The main causes being sepsis, heart failure, transplantation, and tumour lysis. (Sutherland and Kwiatkowski (2017). There is increasing emphasis on calculating the risk of AKI and early treatment (KDIGO 2012). The paediatric RIFLE criteria stratify AKI in children into five groups (R = risk, I = injury, F = failure, L = loss of kidney function, E = end-stage renal disease), enabling earlier recognition and intervention (NICE 2019). Approximately 6% of children with AKI require renal replacement therapies with a survival rate of 55–60% (Sutherland and Kwiatkowski 2017).

CAUSES

The causes of AKI in childhood are commonly divided into three groups: prerenal, intrinsic, and postrenal. Prerenal injury occurs when blood flow to the kidney is reduced as in cardiac insufficiency, renal vein or renal artery thrombosis, and hypovolaemia. In infants and small children, hypovolaemia is commonly due to dehydration following gastrointestinal losses. Studies have shown that AKI in childhood due to dehydration is largely preventable with early management.

Intrinsic renal disorders are those that occur following damage to renal parenchymal cells. These include malignancy, congenital malformation, glomerulonephritis, and haemolytic uraemic syndrome (HUS). Postrenal disorders include urethral obstruction (valves, phimosis), ureteral obstruction, and neurogenic bladder. These conditions require intervention by a paediatric urologist with nephrology liaison.

TREATMENT

NICE guidance (2019) for AKI covers care and management for children and young people, as well as adults. It is not necessary to refer children or young people to a paediatric nephrologist when there is a clear cause for AKI and the condition is responding promptly to medical management. However, the guidance also states that management of AKI needs to be discussed with a paediatric nephrologist as soon as possible and within 24 hours of detection when one or more of the following is present:

- a possible diagnosis that may need specialist treatment (e.g., vasculitis or glomerulonephritis);
- AKI with no clear cause;
- poor response to treatment;

- complications associated with AKI;
- stage 3 AKI (according to [p]RIFLE, AKIN, or KDIGO criteria);
- renal transplant;
- CKD stage 4 or 5.

Children should also be referred following recovery, if there are ongoing signs such as proteinuria or hypertension.

If RRT is needed, the type depends on the circumstances, the skill of the nursing staff, and the therapies available. Traditionally, PD has been the treatment of choice for children with AKI in renal centres. The advantage of PD is that it can be provided as a continuous therapy, which does not require vascular access. In addition, PD does not rely on specialist nursing expertise, although prior experience with this therapy is advisable if using an automated machine. For units without this expertise, manual PD sets for infants and children are available. Bicarbonate dialysis solutions should be considered for use in infants or children who have lactate intolerance.

PD in AKI must be commenced as soon as possible, and there is therefore a risk of leakage. Small volumes of 10–20 ml kg⁻¹ (300–600 ml m⁻²) of continuous cycling therapy are recommended to prevent complications.

Haemodialysis is commonly used to treat children with AKI cared for within paediatric renal centres, when PD has failed or is contraindicated. Haemodialysis is suitable for rapid fluid and toxin removal. The disadvantages of this therapy are the need for vascular access, a water supply that is often only available within paediatric nephrology units, and the need for specialist nurses.

Continuous renal replacement therapy (CRRT) in the form of continuous haemofiltration or continuous haemodiafiltration is increasingly seen as the preferred modality for the treatment of AKI in paediatric intensive care units (Goldstein 2011). CRRT is often used in critically ill patients on PICU, as it minimises haemo-dynamic perturbations associated with intermittent haemodialysis (Hayes and Christian 2012). Children require vascular access of a sufficient size to deliver appropriate blood flow through the filter. A dual lumen central venous line of a minimum 6.5 fg is recommended. Equipment must be calibrated to deliver blood pump speeds as low as 20 ml min⁻¹. Recommended fluid removal should not exceed 0.02 ml kg⁻¹/min⁻¹. As in haemodialysis the extracorporeal circuit size should not exceed 10% of the child's circulating blood volume. In infants, regular blood priming is necessary if the line volume exceeds the child's extracorporeal volume.

HAEMOLYTIC URAEMIC SYNDROME

Haemolytic uraemic syndrome (HUS) is the leading cause of acute kidney injury in children affecting approximately 1 in 100,000 children per year in the UK (Walsh and Johnson 2018). The Shiga toxin producing *E. coli* (STEC) bacteria cause approximately 90% of HUS cases. Children usually present with bloody diarrhoea, nausea, and vomiting. Consequently, children with HUS are often misdiagnosed with surgical problems. Early investigation of renal function and blood film is essential, and transfer to a tertiary referral centre is recommended (Inward 2008).

Approximately 60% of children with HUS require dialysis during the acute stage of the illness (Sheiring et al. 2010). Supportive treatment such as blood transfusion and treatment of hypertension is also required. Currently, 70% of children with HUS recover renal function. However, approximately 25% need treatment for high blood pressure and CKD management.

Atypical HUS (aHUS) is a rare disorder that may occur in childhood. Atypical HUS is a chronic, progressive condition that causes severe inflammation of blood vessels and the formation of blood clots in small blood vessels throughout the body, a process known as *systemic thrombotic microangiopathy*. Children may present with the symptoms of renal failure but there is often no preceding diarrhoeal illness. Until recently, treatment involved regular plasma exchange or plasma infusion to prevent established kidney disease. However, since 2015, Eculizumab, a human monoclonal antibody that binds to complement C5 and blocks prothrombotic and proinflammatory processes, has been commissioned for the treatment of aHUS (NICE 2015b).

TRANSITION TO ADULT SERVICES

Adolescence is recognised as one of the most rapid phases of human development with physical, emotional, and psychological change (World Health Organisation 2023). Transfer from paediatric to adult renal services during this critical time can be stressful for young people, their carers, and health professionals. Poor adherence to medication regimes is recognized as unintentional risk-taking adolescent behavior. Paediatric and young adult patients typically receive high-quality kidney transplants. However, this group has the highest rate of graft failure (Matsuda-Abedini et al. (2022). A reported 35% of young people lose

their transplant within 36 months of transfer to adult services (Harden et al. 2012).

A seamless, supported transition plan is essential. This should consider clinical, educational, and social outcomes for young people. The transition process should start as early as 11 years of age with involvement from the young person, his or her carers, and health professionals from paediatric and adult teams. Starting to plan their transition as early as possible can lead to a better experience for young people moving from children to adult services. Early planning allows a more gradual process and should begin from the age of 14 years (NICE 2021). Flexibility of the time of transfer is important, and should depend on the individual young person's needs rather than a fixed age.

It is acknowledged that paediatric services differ in terms of staffing resources and patient numbers. The key to successful transition is to manage the expectations of young people and their carers. Preparation for change is essential and joint clinics with multiprofessional adult and paediatric teams are recommended. Young people should be given a choice as to whether parents and carers are present at clinic appointments. Specific young adult clinics where young people can receive support from peers are valuable (You're Welcome 2023). The participation of youth workers, trained to provide social and informal educational support, is recommended. Where possible, the appointment of a hospital youth worker to support young people should be considered (Hilton and Jepson 2012).

CONCLUSION

As this chapter has highlighted, providing treatment for children with renal disorders has different challenges from the adult population. In addition to treating the renal-associated complications, there are the additional issues around growth, development, and the psychosocial impact on the whole family (NHS England 2023).

The British Association of Paediatric Nephrology (<https://ukkidney.org/bapn/>) identifies standards for care, and markers for good practice in the service provision for children and young people. The challenge for all paediatric nephrology services is to ensure that these standards are achieved and the highest-quality care is provided for these children and young people.

REFERENCES

- Agersk, H., Thieson, H.C., Pedersen, B.D. (2021 Dec). Siblings of children with chronic kidney disease: A qualitative study of everyday life experiences. *Journal of Renal Care* 47(4): 242–249. doi: 10.1111/jorc.12389. Epub 2021 May 26. PMID: 34042287.
- Ashby, D., Borman, N., Burton, J., et al. (2019). Renal association clinical practice guideline on haemodialysis. *BMC Nephrology* 20: 379.
- Batte, S., Watson, A.R., and Amess, K. (2006). The effects of chronic renal failure on siblings. *Paediatric Nephrology* 21: 246–250.
- Bierzynska, A. Saleem, M. (2017). Recent advances in understanding and treating nephrotic Syndrome. *F1000Research*, 6(F1000 Faculty Rev): 121.
- Boyer, O. & Bérody, S. (2020). Congenital nephrotic syndrome: is early aggressive treatment needed?—No. *Pediatric nephrology (Berlin, West)*. [Online] 35 (10): 1991–1996.
- Boyer, O. Schaefer, F. Haffner, D., et al. (2021). Management of congenital nephrotic syndrome: consensus recommendations of the ERKNet-ESPN Working Group. *Nature Reviews Nephrology*. [Online] 17 (4): 277–289. <https://pubmed.ncbi.nlm.nih.gov/33514942/> (accessed 9 January 2023).
- Byrne, C., Caskey, F., Castledine, C., et al. (2017). The Renal Association UK Renal Registry 19th annual report. *Nephron* 137 Suppl 1. <https://karger.com/nef/article-pdf/137/Suppl.%201/I/3167322/000481361.pdf> (accessed 9 January 2023).
- Corr, M., McKeaveney, C., Wurm, F., Courtney, A. E., & Noble, H. (2023). The educational needs of adolescent and young adult renal transplant recipients: a scoping review. *Healthcare* 11 (4): 566. <https://doi.org/10.3390/healthcare11040566>
- Cheung, A.K., Chang, T.I., Cushman, W.C., et al. (2021). KDIGO 2021 Clinical practice guideline for the management of blood pressure in chronic kidney disease. *Kidney International* 99 (35): s1–s87.
- de Zan, F., Schmitt, C.P. and Shroff, R. (2022). Hemodiafiltration in the pediatric population. *Seminars in Dialysis* 35 (5): 427–430.
- Department of Health (2006a). *The National Service Framework for Renal Services. Working for Children and Young People*. London: Department of Health.
- Department of Health (2006b). *Transition: Getting It Right for Young People. Improving the Transition of Young People with Long-Term Conditions from Children's to Adult Health Services*. London: Department of Health.
- Dufek, S., Ylinen, E., Trautman, A., et al. (2019). Infants with congenital nephrotic syndrome have comparable outcomes to infants with other renal diseases. *Pediatric Nephrology (Berlin, West)* [Online] 34 (4): 649–655. <https://pubmed.ncbi.nlm.nih.gov/30374605/>.
- ESCAPE trial group, Wuhl, E., Trivelli, A. et al. (2009). Strict blood-pressure control and progression of renal failure in children. *The New England Journal of Medicine* 361 (17): 1639–1650.
- Fischbach, M., Fothergill, H., Zaloszc, A., et al. (2012). Hemodiafiltration: the addition of convective flow to hemodialysis. *Pediatric Nephrology* 27 (3): 351–356.
- Fremaux-Bacchi, V., Kemp, E., Goodship, J. et al. (2005). The development of atypical HUS is influenced by susceptibility factors in factor H and membrane cofactor protein-evidence from two independent cohorts. *JMG Online*, <http://jmg.bmj-journals.com/cgi/content/abstract/jmg.2005.030783v1> (accessed 20 May 2013).
- Gerson, A.C., Wentz, A., Abraham, A.G., et al. (2010). Health-related quality of life of children with mild to moderate chronic kidney disease. *Pediatrics* 125 (2): e349–e357.
- Harden, P.N., Walsh, G., Bandler, N., et al. (2012). Bridging the gap: an integrated paediatric to adult clinical service for young adults with kidney failure. *British Medical Journal* 344: e3718.
- Hilton, D. and Jepson, S. (2012). Evolution of a youth work service in hospital. *Nursing Children and Young People* 24 (6): 14–28.
- Hothi, D.K., Stronach, L., and Sinnott, K. (2016). Home hemodialysis in children. *Hemodialysis International* 20: 349–357.
- Inward, C. (2008). Haemolytic uraemic syndrome. *Paediatrics and Child Health* 18 (8): 364–368.
- Jalanko, H. (2009). Congenital nephrotic syndrome. *Pediatric Nephrology* 24: 2121–2128.
- Krmar, R. F. (2018). White Coat Hypertension from a pediatric perspective. *Acta Paediatrica* 108 44–49.
- KDIGO (2011). KDIGO clinical practice guideline for acute kidney injury. *Kidney International* 2 (suppl. 1): 124–138.
- Lee, J. (2021). Children with kidney disease: An overview of pediatric primary nephrotic syndrome. *Pediatric nursing*. 47 (3): 109–123.
- Lennon, R., Watson, L., and Webb, N. (2009). Nephrotic syndrome in children. *Paediatrics and Child Health* 20 (1): 36–42.
- Lurbe, E., Agabiti-Rosei, E., Cruickshank, J.K., et al. (2016). European Society of Hypertension guidelines for the management of high blood pressure in children and adolescents. *Journal of Hypertension* 34 (10): 1887–1920.
- Madden, I., Blaauw, M., Baugh, N., Rees, L. and Shroff, R. (2020). Chronic peritoneal dialysis in children. *Paediatrics and Child Health* 30 (9): 319–327.
- Matsuda-Abedini, M. Marks, S. Foster, B. (2023). Transition of young adult kidney transplant recipients. *Pediatric Nephrology (Berlin, West)*. [Online] 38 (2): 383–390.
- Marciano, R.C., Bouissou Soares, C.M., Diniz, J.S.S. et al. (2011). Behavioral disorders and low quality of life in children and adolescents with chronic kidney disease. *Pediatric Nephrology* 26 (2): 281–290.

- Michael, M., Brewer, E.D., and Goldstein, S.L. (2004). Blood volume monitoring to achieve target weight in pediatric hemodialysis patients. *Pediatric Nephrology* 19: 432–437.
- Mitsnefes, M.M. (2012). Cardiovascular disease in children with chronic kidney disease. *Journal of the American Society of Nephrology* 23 (4): 578–585.
- Mohammad, D., Kapur, G. (2023). Post-kidney transplant hypertension in children. In: Shapiro, R., Sarwal, M.M., Raina, R., Sethi, S.K. (eds.) *Pediatric Solid Organ Transplantation*. Springer, Singapore. https://doi.org/10.1007/978-981-19-6909-6_17
- Mondozi, M.A., Baker, R.A.U., and Wilson, D. (2015). The child with fluid and electrolyte imbalance chapter 24. In: *Wong's Nursing Care of Infants and Children 10th Edition* (ed. M.J. Hockenberry and D. Wilson), 945–995. St. Louis: Elsevier.
- National Health Service (NHS) Blood and Transplant. (2022). *Annual Report on Kidney Transplantation*. NHS Blood and Transplant in collaboration with NHS England. <https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/27956/kidney-annual-report-2021-22.pdf> (accessed 9 January 2023).
- National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents. (2005). *The Fourth Report on the Diagnosis, Evaluation, and Treatment of High Blood Pressure in Children and Adolescents*. Bethesda, MD: National Heart, Lung, and Blood Institute, National Institute of Health. http://www.nhlbi.nih.gov/health/prof/heart/hbp/hbp_ped.pdf (accessed 13 June 2018).
- National Institute for Health and Care Excellence (NICE) Clinical Guidance (2019). *NG148 Acute Kidney Injury: Prevention, Detection and Management*. London: NICE.
- National Institute for Health and Care Excellence (NICE) Clinical Guidance (2021). *NG203 Chronic Kidney Disease : Assessment and Management*. London: NICE.
- National Institute for Health and Care Excellence (NICE) Clinical Guidance (2015b). *Eculizumab for Treating Atypical Haemolytic Uraemic Syndrome*. London: NICE.
- National Institute for Health and Care Excellence (NICE) Clinical Guidance (2016). *Transition from children's to adults' Services*. London: NICE.
- National Institute for Health and Care Excellence (NICE) (2017). *Immunosuppressive Therapy for Kidney Transplant in Children and Young People*. London: Technology Appraisal Guidance NICE.
- National Institute for Health and Care Excellence (NICE) (2018). Renal replacement therapy and conservative management NG107 Overview | Renal replacement therapy and conservative management | Guidance | NICE (Accessed September 2023).
- NHS England (2023). Paediatric medicine renal service specification. Available at NHS England » Paediatric medicine renal service specification (accessed September 2023).
- NHS England (2015). E03/P/b Rituximab for Steroid Sensitive Nephrotic Syndrome in Children. Available at 'You're Welcome': establishing youth-friendly health and care services - GOV.UK (www.gov.uk) (accessed September 2023).
- Oveyssi, J., Manera, K.E., Baumgart, A., et al. (2021). Patient and caregiver perspectives on burnout in peritoneal dialysis *Peritoneal Dialysis International* 41 (5): 484–493.
- Oomen, L., Bootsma-Robroeks, C., Cornelissen, E., De Wall, E., Feitz, W. (2022). Pearls and pitfalls in pediatric kidney transplantation after 5 decades. *Frontiers in Paediatrics* <https://doi.org/10.3389/fped.2022.856630>.
- Preka, E., Shroff, R., Stronach, L., Calder, F., and Stefanidis, C.J. (2021). Update on the creation and maintenance of arteriovenous fistulas for haemodialysis in children. *Pediatric Nephrology* 36: 1739–1749.
- Public Health England, Department of Health (2017). Immunisation against infectious disease. Chapter 7: Immunisation of individuals with underlying medical conditions.
- National Kidney Foundation (2006). Clinical practice guidelines for peritoneal dialysis adequacy update (2006). www.kidneyfoundation.cachefly.net/Professionals/KDOQI/guideline_upHD_PD_VA/index.htm (accessed 20/2/23).
- Nephrotic Syndrome Trust (2023). NeST | Nephrotic Syndrome Trust (nstrust.co.uk) (accessed 23/2/23).
- Norman, K. Christian, M. (2022). Idiopathic nephrotic syndrome: a clinical approach. *Paediatrics and Child Health* [Online] 32 (7): 241–246.
- Qizilbash, L., Cleghorn, S., and McAlister, L. (2020). Kidney diseases, Chapter 13. In: *Clinical Paediatric Dietetics*, 5e (ed. V. Shaw), 238–286. Chichester: John Wiley and Sons.
- Renal Association (2019). Clinical practice guideline haemodialysis. www.ukkidney.org/renal.org/files/FINAL-HD-Guideline.pdf (accessed 15/2/23).
- Renal Association (2018). *Guidelines for Living Donor Kidney Transplantation*, 13.3: 286 https://bts.org.uk/wp-content/uploads/2018/07/FINAL_LDKT-guidelines_June-2018.pdf (accessed September 2023).
- Rees, L., Schaefer, F., Schmitt, C.P., Shroff, R., Warady, B.A. (2017). Chronic dialysis in children and adolescents: challenges and outcomes. *Lancet Child Adolescent Health* 1 (1): 68–77.
- Rees, L., Shaw, V., Qizilbash, L., et al. (2021). Pediatric Renal Nutrition Taskforce. Delivery of a nutritional prescription by enteral tube feeding in children with chronic kidney disease stages 2–5 and on dialysis-clinical practice recommendations from the Pediatric Renal Nutrition Taskforce. *Pediatric Nephrology* 36 (1): 187–204.
- Ring, P.A. and Camille, C.J. (2015). The child with renal dysfunction chapter 25. In: *Wong's Nursing Care of Infants and Children 10th Edition* (ed. M.J. Hockenberry and D. Wilson). St. Louis: Elsevier.
- Santos, F., Díaz-Anadón, L., Ordóñez, F.A., and Hafner, D. (2021). Bone disease in CKD in children. *Calcified Tissue International* 108: 423–438.
- Office for Health Improvement and Disparities (2023). You're Welcome: Establishing youth-friendly health and care services.

- Seeman, T. (2007). Hypertension after renal transplantation. *Paediatric Nephrology* 24: 959–972.
- Smith, H. A., Moore, Z., Tan, M. (2019). Cohort study to determine the risk of pressure ulcers and developing a care bundle within a paediatric intensive care unit setting. *Intensive & Critical Care Nursing* [Online]. 5368–5372.
- Shaw, V. and McCarthy, H. (2020). Chapter 1 principles of paediatric dietetics. In: *Clinical Paediatric Dietetics*, 5e (ed. V. Shaw), 3–22. Chichester: John Wiley and Sons.
- Sheiring, J., Rosales, A., and Zimmerhackl, L.B. (2010). Clinical practice. Today's understanding of the haemolytic uraemic syndrome. *European Journal of Pediatrics* 169 (1): 7–13.
- Sinha, R., Saha, A. and Samuels, J. (2019). American Academy of Pediatrics Clinical Practice Guidelines for Screening and Management of High Blood Pressure in Children and Adolescents: What is new? *Indian Pediatrics* 56: 317–321.
- Snauwaert, E., Wagner, S., Jawa, N. A., et al. (2022). Implementing a fluid volume management program to decrease intra-dialytic hypotensive events in a paediatric in-centre haemodialysis unit: a quality improvement project. *Pediatric Nephrology* 37: 1105–1115.
- Sutherland, S.M. and Kwiatkowski, D.M. (2017). Acute kidney injury in children. *Advances in Chronic Kidney Disease* 24 (6): 380–387.
- Trautmann, A., Vivarelli, M., Samuel, S., et al. (2020). IPNA clinical practice recommendations for the diagnosis and management of children with steroid-resistant nephrotic syndrome. *Pediatric Nephrology (Berlin, West)* [Online] 35 (8): 1529–1561.
- UK Renal Registry (2022). *UK Renal Registry 24th Annual Report – data to 31/12/2020*. Bristol, UK. Available from <https://ukkidney.org/audit-research/annual-reprt> (accessed 9 January 2023).
- Walsh, P. R. and Johnson, S. (2018). Treatment and management of children with haemolytic uraemic syndrome. *Archives of disease in childhood* [Online] 103 (3): 285–291.
- Waby, K., Helm, K., and Watson, A.R. (2005). Preparing children for kidney transplantation through play. *British Journal of Renal Medicine* 10 (4): 9–11.
- Weaver, D.J. and Mitsnefes, M. (2018). Cardiovascular disease in children and adolescents with chronic kidney disease. *Seminars in Nephrology* 38 (6) 559–569.
- Williams, A. (2012). Paediatric renal transplantation. *Paediatrics and Child Health* 22 (8): 346–350.
- Willock, J. and Jewkes, F. (2000). Making sense of fluid balance in children. *Paediatric Nursing* 12 (7): 37–42.
- Wolff, T. (2021). Parallel planning in childhood disability. *Developmental Medicine and Child Neurology* 63: 241–241. <https://doi.org/10.1111/dmcn.14753>

LEARNING OUTCOMES

- to describe the historical background to kidney nutrition and dietetics.
- to evaluate nutritional management in the pre-dialysis phase.
- to identify the dietary principles of haemodialysis (HD) peritoneal dialysis (PD) and transplantation.
- to discuss the role of the nurse in giving dietary advice.

INTRODUCTION

Dietary treatment has always been regarded as an important part of managing patients with chronic kidney disease (CKD), before and during kidney replacement therapy (KRT). During the 1960s many patients were treated with diet alone. The kidney diet was adapted to dialysis and transplantation once these modes of KRT became available during the 1970s and early 1980s. The common problems of chronic fluid overload, hyperphosphataemia, increased cardiovascular risk, and malnutrition can lead to long-term complications if not resolved and adversely affect outcome of treatment and the quality of life of patients with kidney disease, who may require treatment for many decades. This chapter will address the important issues of dietary management and the role it plays in the overall treatment of CKD.

HISTORICAL REVIEW OF DIETARY MANAGEMENT

PRE-DIALYSIS TREATMENT (1960–2000)

HD was only accepted as a regular form of KRT for selected patients at the end of the 1960s. Prior to this period, patients approaching end-stage kidney disease (ESKD) with gastrointestinal symptoms were advised to follow a very-low-protein diet (VLPD). The best-known diet at the time was the Giovanetti diet, containing 20 g protein of high biological value (HBV) to cover essential amino acid

requirements. An intake of 50 kcal kg⁻¹ body weight (BW) was recommended to prevent loss of muscle and maintain nitrogen balance. This diet was prescribed to selected patients with a creatinine clearance of 3 ml min⁻¹ or a plasma urea level of 33 mmol l⁻¹ (200 mg dl⁻¹) and was the only treatment available to improve the well-being of patients until regular HD treatment became available.

It became apparent in later years that a badly managed protein-reduced diet contributed to malnutrition before patients started HD. This prolonged the rehabilitation period and also negatively contributed to the outcome of treatment, with an increased morbidity and mortality (Ikizler and Hakim 1996).

During the 1980s there was a renewed interest in protein allowance, as protein restrictions in partially nephrectomised rats delayed the progression of kidney disease. This was the hyperfiltration/hyperperfusion hypothesis proposed by Brenner (1983), although it was more difficult to prove the same effect in humans. High-energy diets containing no more than 0.6 g protein kg⁻¹ BW day⁻¹ were prescribed during the early stages of chronic kidney disease to asymptomatic patients, who not surprisingly found this difficult to follow for extended periods of time.

In the United States, the National Institutes of Health (NIH) stated in 1993 that the nutritional health of a patient prior to dialysis was an important indicator of outcome and that all patients were entitled to receive a nutritional assessment by a trained kidney dietitian. In the absence of obvious malnutrition, a moderate low-protein diet of up to

0.7–0.8 g protein kg⁻¹ BW day⁻¹ should be prescribed. When malnutrition was present, the amount of energy was increased and the amount of protein raised to 1.0–1.2 g kg⁻¹ to allow for nutritional repletion or to counter the catabolic effects of stress. Dietary prescriptions should also include guidelines for energy, fat, carbohydrate, fluid, sodium, phosphate, and potassium, as well as other nutrients and micronutrients (NIH 1993). The NIH had also commissioned a large, multicentre study to ascertain once and for all the efficacy of low-protein diets. The Modification of Diet in Renal Disease (MDRD) study compared diets with different levels of protein reduction at different levels of kidney impairment. The diets ranged from usual intake to VLPD supplemented with ketoacids and combined with phosphorus restriction. The results of this 2-year study, which had been launched in 1985, were finally published in 1994 (Klahr et al. 1994).

The MDRD study showed that, in the absence of severe proteinuria and hypertension, a reduction of protein intake by 0.2 g kg⁻¹ BW resulted in a modest reduction in the rate of progression. There appeared to be no further advantage in using a VLPD supplemented with essential amino acids. However, it did reveal that subjects accustomed to a 'Western' diet containing typically >1.2 g protein kg⁻¹ day⁻¹ found it very difficult to achieve the designated protein restrictions of <0.6 g protein kg⁻¹ day⁻¹. The report cautioned that, whilst lowering blood pressure and protein intake appeared to be safe, both must be carefully monitored.

Several meta-analyses were subsequently conducted, which included studies such as the MDRD study. Fouque et al. (2000), Pedrini et al. (1996), and Ginn et al. (1999) concluded that dietary protein reduction effectively slows the progression of kidney damage due to diabetes mellitus (DM) and also those without diabetic kidney disease.

On the basis of these analyses as well as expert opinion, National Kidney Foundation (NKF)/Dialysis outcomes quality initiative (DOQI) published the 'Clinical practice guidelines for nutrition in chronic renal failure' (Kopple et al. 2000) and the European Dialysis and Transplant Nurses Association/European Renal Care Association also published guidelines shortly afterwards. The suggested protein and energy requirements for patients with advanced chronic kidney disease (CKD), not on dialysis, recommended 0.6–1 g protein kg⁻¹ day⁻¹ at a GFR of 25–50 ml min⁻¹ and a protein intake of 0.6–0.75 kg⁻¹ day⁻¹ at a GFR of <25 ml min⁻¹ and take the patient's ideal body weight (IBW)¹ as well as the residual renal function into consideration.

The debate about whether to reduce protein (and how low to go) continues to this day. In support of protein reduction, a low-protein diet will reduce the burden of waste products that have to be removed: nitrogen compounds,

acids, phosphate, and also potassium. This could potentially reduce symptoms of uraemia and control the development of problems such as acidosis and bone disease.

The main deleterious effect of the low-protein diet is the risk of malnutrition. Energy requirements are difficult to meet (although not impossible) without resorting to sources of carbohydrate and fat, which may have an impact on cardiovascular disease (CVD). Vitamin and mineral intakes also have to be monitored closely. Those clinicians not in favour of low-protein diets argue that the risk of malnutrition outweighs any benefits that may be gained from the (very moderate) reduction in the rate of decline in kidney function (Johnson 2009). The most recent Cochrane review, which analysed the results from 17 studies and 2996 patients, concluded that very low protein diets (0.3–0.4 g protein/kg/day) probably reduce the number of people (non-diabetic adults) who progress to ESKD; however, the impact on nutritional status and quality of life needs further investigation (Hahn, Hodson, and Fouque 2020).

As there are many different elements to patient care prior to starting dialysis, a more realistic approach to protein recommendations is usually taken.

CURRENT CONCEPTS OF PRE-DIALYSIS DIETARY INTERVENTION

The nutritional content of the diet should be specifically adapted to each patient's individual needs and personal circumstances. This should result in the reduction of metabolic waste products, which can otherwise accumulate as chronic disease progresses. Most patients will receive some nutrition information in the pre-dialysis phase, although it is quite variable and dependent on dietetic staffing levels. The Renal Nutrition Group of the British Dietetic Association (BDA) has designed a flow chart which outlines the nutritional care of a person with CKD (Figure 12.1). Therefore, in CKD stages 1–3 the focus is on weight management, diabetes control, hypertension, and lipid management as described in the National Institute for Health and Care Excellence (2021) clinical guideline NG203. This guideline also describes four points regarding lifestyle advice relevant to the management of CKD:

- 1.4.6 Encourage exercise, achieve a healthy weight, and stop smoking.
- 1.4.7 Offer dietary advice about potassium, phosphate, calorie, and salt intake appropriate to the severity of CKD.
- 1.4.8 If dietary intervention is agreed, provide it alongside education, detailed dietary assessment and supervision to ensure malnutrition is prevented.
- 1.4.9 Do not offer low-protein diets (less than 0.6–0.8 g kg⁻¹ day⁻¹) to adults with CKD.

¹ See Appendix 12.A for calculation of IBW.

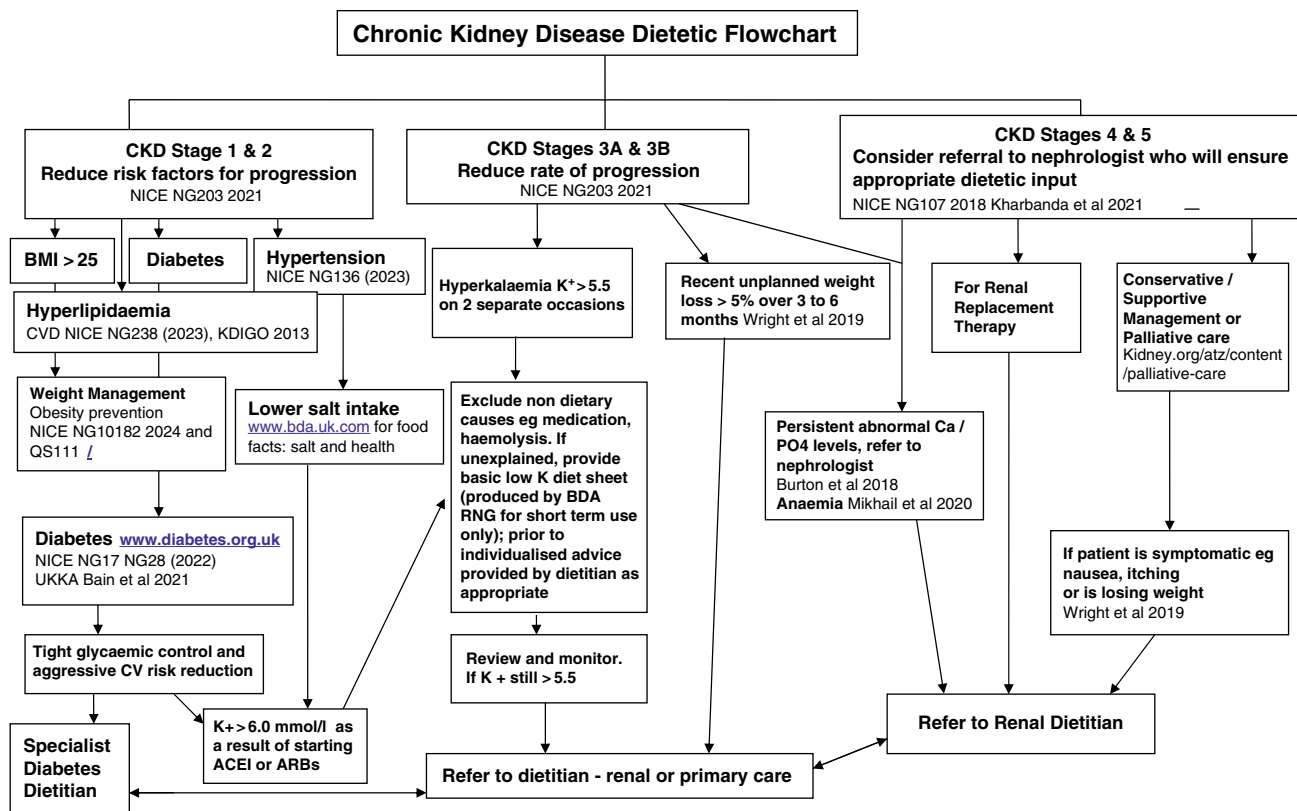


FIGURE 12.1 Flow chart for dietary treatment of chronic kidney disease (CKD); stages 1–5.

The UK NICE guideline (2021) recommends shared decision-making, supporting self-management of blood pressure, smoking cessation, exercise, diet, and medication, including giving access to medical data. From stage 3 (usually 3b) to stage 5, the problems of preventing and controlling renal bone disease, hyperkalaemia, anaemia, acidosis, and malnutrition come to the fore. The NICE (2021) guideline cover these conditions from a medical perspective.

The UK Kidney Association (formed from the Renal Association (RA) and British Renal Society) have produced specific clinical guidelines that cover the key elements of care, many of which also have nutritional implications that will be referred to in the relevant sections:

- Hypertension in adults; diagnosis and management including proposals for blood pressure management in patients with CKD (updated commentary on NICE guidelines (NG136), and KDIGO guideline 2021) (Fish et al. 2022)
- Exercise and lifestyle in CKD (Baker et al. 2021)
- Clinical practice guidelines for management of hyperglycaemia in adults with diabetic kidney disease (Bain et al. 2021)

- Anaemia of CKD (Mikhail et al. 2020)
- Commentary on the NICE Guideline on Renal Replacement Therapy and Conservative Management (Kharbanda et al. 2020)
- Undernutrition in CKD (Wright et al. 2019)
- Commentary on KDIGO guideline on diagnosis, evaluation, prevention, and treatment of CKD mineral and bone disorders (Burton et al. 2018)

NUTRITIONAL REQUIREMENTS

Protein

Protein is an important nutrient for the repair and maintenance of tissue and for growth. Quantity as well as quality must be taken into account.

Quantity The level of dietary protein intake should maintain nitrogen balance (in a well-nourished adult) or be sufficient for growth (in children) and repair (in patients recovering from malnutrition or illness). For instance, if a patient consumes a high-protein diet (>1.2 g kg^{-1} IBW), a reduction to 1.0 g kg^{-1} IBW may initially be sufficient, which can be

reduced to 0.8 g kg^{-1} IBW if kidney function deteriorates at a later stage. This is an acceptable protein allowance for long-term use, and it meets the maintenance requirement of 0.66 g kg^{-1} advised by WHO/FAO. The recent UKKA guideline 'Undernutrition in CKD' (Wright et al. 2019) recommended a protein intake of $0.8\text{--}1.0 \text{ g kg}^{-1}$ as realistic and required an energy intake of $30\text{--}40 \text{ kcal kg}^{-1} \text{ day}^{-1}$ depending on age and physical activity to prevent malnutrition; as stated above, the NICE guidelines NG203 (2021) do not support an intake below $0.6 \text{ g kg}^{-1} \text{ day}^{-1}$. Interestingly, the latest 'Kidney Disease Outcomes Quality Initiative' KDOQI (2020) guidelines suggest lowering protein intake to $0.55\text{--}0.60 \text{ g kg}^{-1} \text{ day}^{-1}$, which is lower than the previously recommended $0.8 \text{ g kg}^{-1} \text{ day}^{-1}$ in adults without diabetes with CKD stages 3-5. A very low protein diet supplemented with keto acid analogs is also suggested as an option, under close clinical supervision. For adults with diabetes a dietary protein intake of $0.6\text{--}0.8 \text{ g kg}^{-1} \text{ day}^{-1}$ is suggested 'to maintain a stable nutritional status and optimize glycaemic control' although the evidence for this is cited as 'opinion' only.

Quality The quality of protein is affected by its digestibility and amino-acid content. Meat, fish, eggs, milk, and soy protein are usually referred to as containing HBV protein because of the levels of essential amino acids when compared with a reference protein. Proteins from plant sources (cereals, vegetables, pulses, and nuts) may be limited in lysine, threonine, methionine, and cysteine and have poorer digestibility. Despite this, the amino acid content of a UK vegetarian diet is comparable with UK omnivores. Rice-based vegetarian diets may have poorer amino acid content (compared with wheat-based diets) as well as lower digestibility. In order to ensure that a reduced-protein diet contains adequate levels of all the amino acids, it is particularly important for vegetarians to have proteins from a variety of sources, including cereals, pulses, and legumes.

Energy

Protein, fat, carbohydrate, and alcohol all contribute to a person's energy intake.

Quantity Example: to calculate energy requirements for a 70 kg person (IBW):

$$\begin{aligned} 70 \times 30 - 35 \text{ kcal} & (126 - 150 \text{ kJ}) \\ & = 2100 - 2450 \text{ kcal} (8.8 - 10.3 \text{ MJ}) \end{aligned}$$

The range of energy requirements, $30\text{--}35 \text{ kcal kg}^{-1}$, is similar to the result obtained using the Schofield equations

for basal metabolic rate and assumes a physical activity level of 1.3–1.4, which is low (Todorovic and Mafrić 2018). Patients with increased metabolism due to infection, injury, or increased activity levels should have their requirements calculated using equations such as Schofield or Oxford with appropriate factors added for metabolic stress and activity levels.

Quality The quality of food that provides energy is as important as the quantity of food. CVD and some cancers are associated with a high proportion of saturated fat in the diet. Hypertriglyceridaemia (common in patients with kidney disease) is associated with high intakes of rapidly absorbable carbohydrates and alcohol. If a protein reduction has been advised, there has to be an increase in calories to make up the deficit. This could take the form of monounsaturated fat (olive oil) and carbohydrates with a medium-to-low glycaemic index (pasta, basmati rice, new boiled potatoes, some fruits). Several systematic reviews have focused on overall dietary quality and incidence of CKD. Quintela et al. (2021), Brown et al. (2021), and van Westing et al. (2020) highlighted observational, cross-sectional, case control, and cohort studies which described dietary patterns such as Mediterranean diet and DASH diet (both are high in vegetables, fruits, whole grains, fibre, legumes, plant-based proteins, unsaturated fats and nuts; and lower in processed meats, refined carbohydrates, and sweetened beverages) or simply increased intake of fruit and vegetables having a nephroprotective effect. These diets were associated with lower levels of albuminuria and inflammatory markers, higher levels of GFR, and ultimately lower CV and CKD risk.

Micronutrients: vitamins and minerals

Vitamins and minerals regulate metabolic pathways, including metabolism of the macronutrients protein, carbohydrate, and fat. Some of the most observable clinical features of uraemia (anaemia and renal bone disease) are caused, or at least exacerbated, by vitamin and mineral deficiencies. These can arise because uraemia alters their serum levels and body stores and also interferes with their function. Drug interactions can affect the absorption and utilisation of minerals (such as calcium, iron, zinc, and magnesium) and vitamins (such as B_6 , folate, and B_{12}) (Jankowska et al. 2017).

Dietary reductions that limit protein, phosphate, and potassium intake will inevitably limit the intake of various micronutrients. A low-protein diet can contain low levels of B vitamins (B_1 , B_2 , B_6 , B_{12}), iron, calcium, and zinc (Hadfield 1992). A low-potassium diet will limit intake of folic acid, vitamins C and E, as well as phytochemicals

such as fructo-oligosaccharides, phytosterols, and polyphenols. A review by Steiber and Kopple (2011) found that vitamin deficiencies (particularly B₁ and B₆) in CKD stages 3–5 were common, with intake of other B vitamins decreasing with lower protein intake.

However, there may be reduced kidney losses of some nutrients. Vitamin supplements containing the fat-soluble vitamins A and E are contraindicated in patients with kidney disease. Vitamin A metabolites are less well excreted and accumulate over time; toxicity has been reported in patients receiving total parenteral nutrition containing a high dose of vitamin A. High-dose vitamin E supplementation may potentially disrupt the clotting mechanisms. The KDOQI guidelines for nutrition (Ikizler et al. 2020) stated that ‘it is reasonable to not routinely supplement vitamin A or E because of potential toxicity’ (opinion).

A recent systematic review assessed the evidence for a variety of specific supplements on progression of CKD, including vitamin D and analogues, omega-3 polyunsaturated fatty acid (omega-3 PUFA), dietary fiber, coenzyme Q10 (CoQ10), and biotics, but concluded that the evidence for proteinuria, kidney function, and inflammation was low and did not appear to improve prognosis (Lin et al. 2021).

HYPERTENSION

Sodium (Na) and fluid retention occur in most types of kidney disease and contribute to high blood pressure. The National Institute for Health and Care Excellence (2022) guideline NG136 and the KDIGO (2021) guidelines (Cheung et al. 2021) recommend that, to improve blood pressure control, patients should be advised to reduce dietary salt and alcohol intake, stop smoking, achieve a healthy weight, and take regular exercise (150 minutes a week). NICE guidelines recommend aiming for levels of below 140/90 mmHg, or 130/80 mmHg if the person has diabetes or high levels of proteinuria. This lower level (130/80 mmHg) is supported by UKKA for patients at elevated cardiovascular risk (Fish et al. 2022). KDIGO recommends aiming for systolic blood pressure of <120 mmHg based largely on evidence from the SPRINT trial, which showed lower rates of fatal and non-fatal cardiovascular events.

A moderate salt-reduced diet (about 80–120 mmol Na) will facilitate the action of antihypertensive medication such as diuretics and the commonly used angiotensin converting enzyme (ACE) inhibitors. A systematic review found that salt reduction not only reduced blood pressure but also reduced proteinuria; however, longer-term studies are needed to see if this improved progression of kidney disease and reduction of cardiovascular events in people

with CKD (McMahon et al. 2015). UKKA guidelines and also the current government Food Standards Agency (FSA) guidelines for the general population recommend a maximum salt intake of 6 g day⁻¹ or 100 mmol sodium. However, KDIGO (2021) guidelines recommend a sodium intake of 90 mmol, which is equivalent to a salt intake of 5 g day⁻¹. In practice, this is not simple because many people rely on the purchase of processed foods (see Appendix 12.B). About 80% of our salt intake is hidden in processed foods, including staple food items such as bread and breakfast cereals. There are ethnic differences in salt intake whereby some ethnic populations in the UK who still cook traditional meals ‘from scratch’ nonetheless use a lot of salt in cooking. It is important to be aware of the barriers and facilitators which will influence behaviour change in these populations (de Brito Ashurst et al. 2010).

Patients should be advised as follows:

- Prepare meals using fresh ingredients.
- Use spices and herbs to add flavour to food.
- Only use a little salt in meal preparation.
- Avoid adding salt to food after preparation.
- Avoid excessive amounts of salty foods such as cured and processed foods; this includes takeaway meals.
- Avoid using salt substitutes containing potassium salts such as potassium chloride (KCl).
- Avoid meals prepared with monosodium glutamate. This is added to enhance the taste of food in restaurants, takeaway outlets, and ready-to-eat meals sold in supermarkets.
- Read food labels (look at traffic light system) and check for additives like monosodium glutamate and salt substitutes. Note that 1 mmol Na = 23 mg Na; 2 g (2000 mg) Na = 5 g NaCl = 90 mmol Na.

A small proportion of patients are ‘salt losers’ (due to a specific renal pathology) and need to add salt to their meals and/or use salt supplements.

CARDIOVASCULAR RISK AND HYPERLIPIDAEMIA

The traditional risk factors of age, gender, lipid levels, and blood pressure contribute to risk of CVD in patients with kidney disease; additionally, other risk factors include calcium and phosphorus imbalance, hyperhomocysteinaemia, inflammation, and possibly anaemia (Holt and

Goldsmith 2010). The National Institute for Health and Care Excellence (2014 updated 2023) CG181 guidelines on cardiovascular disease do not recommend the use of a risk assessment tool (such as QRISK2) to assess CVD risk in people with an estimated glomerular filtration rate (eGFR) less than $60 \text{ ml min}^{-1} 1.73 \text{ m}^{-2}$ and/or albuminuria, simply stating that these people are at increased risk of CVD.

Recommendations from the K/DOQI (2003a) guidelines stated that CKD was a high-risk factor for CVD and that 'major findings from randomised trials in the general population are applicable to patients with CKD, until proven otherwise'. More recent intervention trials in the kidney population, summarized in KDIGO clinical practice guideline for Lipid Management in CKD (2013), have to some extent supported this statement, with the caveat that some unexpected findings show that the pathophysiology of CVD in kidney patients is different from the 'norm' – perhaps because of the additional risk factors just described.

Heart UK suggests LDL $< 3 \text{ mmol/l}$, total cholesterol $< 5 \text{ mmol l}^{-1}$, non-HDL $< 4 \text{ mmol}$, HDL cholesterol > 1 (men) and 1.2 (women) fasting triglycerides $< 1.7 \text{ mmol l}^{-1}$, HbA1c < 6.5 ($48 \text{ mmol mmol}^{-1}$).

As well as BMI, the National Renal Data Set recommends that waist and hip circumference should be measured. An excess of body fat, particularly round the waist, is linked with metabolic disturbances, including raised inflammatory cytokines and insulin resistance. In patients with CKD, a raised waist: hip ratio has been associated with increased myocardial infarction and fatal coronary artery disease (Elsayed et al. 2008). Significant correlations have been shown between the presence of inflammation (measured by CRP [C-reactive protein], TNF α [tumour necrosis factor], and fibrinogen) and carotid plaques in patients preparing for dialysis, who have simultaneously demonstrated signs of muscle/protein wasting (low serum creatinine, LBM [lean body mass], and urea nitrogen appearance); the so-called malnutrition–inflammation–atherosclerosis (MIA) syndrome (Stenvinkel 2003).

The UKKA carried out a systematic review of the literature in order to develop their clinical practice guideline: exercise and lifestyle in CKD (Baker et al. 2021). Blood pressure and lipid levels should be well controlled using a combination of lifestyle changes and medication, including ACE inhibitors for blood pressure and statins and ezetimibe for cholesterol. Lifestyle changes include weight loss where necessary to achieve a healthier BMI, having a cardioprotective diet, stopping smoking, avoiding excess alcohol, and taking regular exercise (NICE NG203 section 1.2, NICE CG181 section 1.3. 2014 updated 2023 NG238, Baker et al.

2021). Exercise also contributed to better health-related quality of life in the non-dialysis CKD population (Baker et al. 2021).

The systematic review by Palmer et al. (2017) found some evidence for beneficial effects of dietary interventions in CKD, including use of the Mediterranean diet. A later systematic review focusing on dietitian-led interventions and whole diet, dietary pattern interventions also found improved CV risk factors (decreased LDL, decreased SBP, improved BMI) in some small studies (70–100 subjects) in response to an increase in fruit and vegetable intake, in stage 3–4 CKD (Brown et al. 2021). More good-quality studies are still needed to elucidate the role of diet, exercise, and weight reduction in reducing the risk of CVD and MIA in patients with CKD.

INTERVENTIONS IN PATIENTS WITH DIABETES

The results of the Diabetes Control and Complications Trial (DCCT) (Type 1 diabetes) and the UK Prospective Diabetes Study (UKPDS) (1998) (Type 2 diabetes) showed that careful control of blood glucose and hypertension significantly decreases the renal complications of diabetes which often begin with the appearance of microalbuminuria (UKPDS 1998; Yale 2005). Observational studies also indicate improved cardiovascular risk with good glycaemic control. The Diabetes UK and UKKA guidelines (Bain et al. 2021) recommend a target HbA1c of 6.5–7.5% (48 – 58 mmol mol^{-1}) for type-1 (CKD 2 with variable microalbuminuria in younger people) and type-2 diabetes (CKD 1–2, people aged < 40 or diet controlled at any age) stating the benefits mentioned above. Lifestyle self-management (diet, exercise, smoking cessation, and healthy weight) still forms the base of the kidney and heart risk factor management, pyramid illustrated in KDIGO 2022; however, new drug treatments, including SGLT2 inhibitors (which block renal glucose absorption) and GLP-1 receptor antagonists (which improve insulin sensitivity), have been accepted by KDIGO as well as NICE guidelines and UKKA guidelines, and the former show promising effects of slowing progression of kidney disease in people with and without diabetes.

A Cochrane systematic review by Robertson et al. (2007) concluded that reducing protein intake does seem to slow progression of diabetic nephropathy, although in a non-significant way; that is, increasing time to dialysis by only 2 months. They noted that compliance with such a protein-reduced diet was difficult to achieve and also added that factors worth considering included changing the type of protein: vegetable versus animal, fish/white meat versus

red meat. This may be a more practical and achievable approach than restricting the amount of protein, but the trials evaluating the effectiveness only involved small numbers of patients. The CARI guidelines also agree that there was insufficient evidence to support the use of lower protein intakes to slow down progression of nephropathy in type-2 diabetes but support the use of 0.75–1g protein/kg/day, as well as a carbohydrate restricted, low iron available, polyphenol enriched diet to slow down progression of DM nephropathy (Chan and Johnson 2012). The Diabetes UK guidelines (2018) base their recommendations regarding protein reduction on the systematic review by Robertson et al. (2007) and later reviews by Nezu et al. (2013) and Rughooputh et al. (2015) and recommend that protein restriction is not routinely used but that a 6-month trial of reduced protein may be initiated and continued if there is a response. KDIGO diabetes management guidelines (2022) suggest 0.8g protein/kg/day for those people with diabetes and not on dialysis together with a healthy diet as previously described (similar to Mediterranean or DASH diet).

With the rising levels of diabetes in the population there needs to be a concerted effort in primary care to maximise blood glucose and blood pressure control, in order to prevent nephrology services from being overwhelmed with patients who have diabetes.

CALCIUM, PHOSPHATE, AND VITAMIN D METABOLISM

The first signs of impaired calcium (Ca) and phosphate (P) homeostasis arise early in kidney impairment (CKD 2) as parathyroid hormone (PTH) levels start to rise. This is due to phosphate retention and impaired hydroxylation (activation) of vitamin D, which results in reduced absorption of Ca from food in the small intestine. The ensuing hypocalcaemia stimulates an increased release of PTH, which, in an attempt to normalise plasma calcium levels, releases calcium and phosphate from the bone (eventually causing weakened bones). As kidney disease progresses, the release of calcium and phosphate from the bone and reduced excretion of phosphate in the urine leads to hyperphosphataemia.

Monitoring of calcium, phosphorus, PTH, calcidiol (25OH vitamin D), and alkaline phosphatase (ALP) is recommended from CKD stage 3a (Burton et al. 2018). Treatment can include the use of calcium supplements, vitamin D (including activated forms, alfacalcidol, and calcitriol), calcimimetics, dietary phosphate restriction, and phosphate binders (Sexton and Vincent 2004). The NICE

guidelines NG203 (2013) and UKKA (2018) recommend that a specialist kidney dietitian should carry out a dietary assessment and give individualised information and advice on dietary phosphate management.

CALCIUM SUPPLEMENTS

The recommended daily calcium intake for patients who require advanced kidney care is 1000–1500 mg. If this is not being achieved (particularly if protein intake is low), calcium supplements may be needed but should be taken in between meals, preferably at bedtime, to maximise calcium absorption.

‘ACTIVE’ VITAMIN D

Vitamin D is a fat-soluble vitamin and is obtained from a small number of foods but mostly from exposure to sunlight (this may be reduced in the elderly and certain ethnic groups). It needs to be converted to an active form by hydroxylation in the liver and kidney. The use of active forms of vitamin D, alfacalcidol, and calcitriol can be troublesome. On the one hand, they reduce PTH levels (which will reduce the negative effects on bone) but, simultaneously, calcium and phosphate absorption from the gut increases, which can lead to hypercalcaemia and hyperphosphataemia if not monitored closely. The precipitation of this excess calcium and phosphate in the soft tissues (blood vessels, coronary arteries, and aortic valves), is considered to be one of the major causes of morbidity and mortality in adults, particularly young adults with ESKD.

NICE guidelines NG203 recommend offering colecalciferol or ergocalciferol to treat vitamin D deficiency in people with CKD and as vitamin D has many metabolic roles, there is a strong rationale for ensuring adequate levels of this hormone, not simply to normalise bone metabolism (Armas and Heaney 2011). Vitamin D deficiency is a modifiable risk factor for elevated PTH. However, the latest UKKA guidelines suggest that calcitriol and vitamin D analogues should not be used routinely but only for severe and progressive secondary hyperparathyroidism.

DIETARY PHOSPHATE REDUCTION

The RA has advised that ‘limiting phosphate intake in patients with CKD3a-5D remains integral in the management of hyperphosphataemia’. Although the optimal time to start a reduction in phosphate intake/commence phosphate binders has not been established, the KDIGO (2017) guidelines recommend:

In patients with CKD G3a–G5D, we suggest limiting dietary phosphate intake in the treatment of hyperphosphatemia alone or in combination with other treatments. It is reasonable to consider phosphate sources (e.g. animal, vegetable, additives) in making dietary recommendations.

The older K/DOQI guidelines (2003b) recommend specific intakes of phosphorus such that:

Dietary phosphorus should be restricted to 800 to 1,000 mg/day (adjusted for dietary protein needs) when the serum phosphorus levels are elevated (1.49 mmol/l (>4.6 mg/dL)) at Stages 3 and 4 of CKD, and >1.78 mmol/l (5.5 mg/dL) in those with kidney failure (Stage 5).

UKKA guidelines suggest ‘a pragmatic and individualized approach to phosphate reduction towards the normal range’ and calcium should be ‘below the upper limit’ of the normal reference range in Stages 3a to 5 CKD.

Calcium and phosphate are obtained from most foods with high protein content. Examples are milk and its products: cheese and yoghurt. Phosphorus also appears in high-fibre cereal products, fish with edible bones, offal, pulses, and nuts. Absorption from the gastrointestinal tract varies between 30% and 80%, and phosphorus from vegetable sources is less bioavailable (20–50%) than animal based phosphate (40–60%) whereas food additives are highly absorbable (80–90%) (Benini et al. 2011) and in fact serum phosphate levels were shown to decrease in a crossover trial of nine patients with CKD3 on a vegetarian diet compared to a meat-rich diet containing similar amounts of phosphorus (Moe et al. 2011).

Appendix 12.D shows high-phosphorus foods, not all of which have alternatives with comparable nutrient content, and therefore total elimination from the diet is not feasible. Hyperphosphataemia is difficult to control by dietary manipulation alone and needs to be combined with phosphate binders. A moderate protein reduction will also tend to reduce phosphate intake, which is one of the arguments in favour of a protein reduction in the pre-dialysis population. However, the impact on other nutrients must always be considered. For example, wholemeal products contain more phosphorus as well as more fibre, yet fibre also improves bowel habits and the general well-being of patients and thus current dietary information needs to be modified in order to take into account not just phosphate content but also bioavailability.

PHOSPHATE BINDERS

Phosphate binding occurs in the stomach and small intestine and reduces the absorption of phosphate into the body. If calcium and aluminium salts are used as oral

binders, these initially dissolve in the acid environment of the stomach and then form an insoluble precipitate with phosphate. This product is eliminated via the gastrointestinal route (not the kidneys). However, a high gastric pH (i.e. less acidic), found generally in the elderly and particularly in people taking H₂-receptor antagonists such as ranitidine, can reduce the effectiveness of the binders and hyperphosphataemia can result.

Phosphate binders should be taken with food, particularly main meals and snacks containing phosphate, and with milk-based nutritional supplements. Ideally, the dose of the binder should be altered to reflect the phosphate content in a particular meal. Pre-emptive use of phosphate binders is not recommended in the UKKA guidelines (Burton et al. 2018) but for those with ‘progressively rising or persistently elevated serum phosphate.’

Both the calcium and aluminium in the binder are absorbed to some extent and this has given rise to worries about aluminium toxicity and calcium overload, with many recent guidelines suggesting that use of calcium-based binders should be restricted (KDIGO 2017, UKKA 2018). Phosphate binders such as sevelamer hydrochloride (Renagel), lanthanum carbonate, and iron-based binders do not contain calcium or aluminium and sevelamer has an added benefit in that it also binds cholesterol. Calcimimetic agents are recommended for use in patients with hyperparathyroidism and control of calcium and phosphate in Stage 5 CKD (Burton et al. 2018).

HYPERKALAEMIA

Plasma potassium levels are tightly controlled in the body and, in order to maintain normal levels, 90% of potassium is usually excreted by the kidney, with the remainder excreted via the gastrointestinal route. Progressive kidney disease is often complicated by hyperkalaemia (plasma potassium >5.5 mmol l⁻¹) and may occur when kidney function has declined to a GFR of 5 ml min⁻¹ despite normal urine output. Hyperkalaemia can also occur at an earlier stage when patients receive ACE inhibitors or angiotensin II receptor binders (ARBs) for blood pressure control. This can be exacerbated if combined with a high intake of potassium-rich foods and is potentially life threatening, particularly as it is not associated with physical warning signs and requires immediate treatment. Both low and high potassium levels were shown to be associated with adverse outcomes in a meta-analysis of 27 international cohort studies (Kovesdy et al. 2018), which also identified a variety of risk factors including albuminuria and diabetes. Dietary and non-dietary causes of hyperkalaemia should be investigated at the same time.

Examples of non-dietary causes are:

- metabolic acidosis;
- increased catabolism (and conditions which cause cell destruction: rhabdomyolysis, gastrointestinal bleed);
- endocrine abnormalities;
- drugs such as potassium supplements (i.e. slow K), some laxatives, potassium-sparing diuretics, ACE inhibitors, ARBs, and non-steroidal anti-inflammatory drugs (NSAIDs);
- constipation (and drugs that exacerbate constipation, for example iron tablets).

DIETARY MANAGEMENT

A dietary intake of no more than 60–70 mmol day⁻¹ (1 mmol kg⁻¹ IBW) is sufficient to prevent or treat hyperkalaemia in the presence of an adequate urine output or dialysis treatment. Dietary sources of potassium are listed in Appendix 12.E. Many foods contain potassium, but vegetables and fruits are major sources; some varieties contain more than others. Staple foods such as potatoes, yam, sweet potatoes, green bananas, and plantain are high in potassium, but should be included in a potassium-reduced diet. However, typical DASH and Mediterranean style diets may contain between 100–150 mmol K (Clase et al. 2020) and there is a growing interest in whether potassium from different foods should be treated differently due to compensatory mechanisms – for example, intracellular accretion and increased gastrointestinal losses which may occur when plant based sources of potassium are consumed (as compared to meat sources) (Clegg et al. 2020).

Potassium-containing salts such as dipotassium phosphate, are used as food additives but in small quantities. Of greater concern is the use of potassium chloride (KCl) as a substitute for sodium chloride as part of the food manufacturers' attempt to reduce the sodium content of food, which was encouraged in the SACN-COT statement on potassium-based sodium replacers (SACN 2017).

Patients should receive dietary advice regarding the potassium content of specific foods, avoiding or at least limiting the quantities eaten of those that are high and perhaps less nutritious. The Renal Nutrition Group of the British Dietetic Association have developed a set of information leaflets that specifically represent different cultural diets in order to ensure dietary adequacy and enjoyment of food in the different cultures in the UK. Cooking techniques such as boiling (and throwing away the cooking water) will remove some of the potassium in vegetables. Cooking methods which *retain*

potassium include cooking in a pressure cooker or microwave, stir-frying, roasting, and casseroles of vegetables.

POTASSIUM AND HIGH-FIBRE FOODS

Constipation is a common problem for patients receiving PD, older, and sedentary patients. High-fibre cereal products are recommended to prevent constipation and can have a beneficial effect on hyperlipidaemia. Some high-fibre foods are high in potassium, although studies have shown that the overall effect of a high-fibre diet on serum potassium was not significant – increasing serum potassium levels by about 0.3 mmol l⁻¹ (Sutton et al. 2014).

POTASSIUM-REDUCING MEDICATION

Potassium binders such as calcium or sodium ion-exchange resin (i.e. calcium or sodium resonium) may be used to control hyperkalaemia. Calcium resonium is a gritty textured powder and is best taken with a sweet drink to mask its taste. Calcium ions (or sodium) are exchanged for potassium ions in the gut and the potassium is then eliminated. The long-term use of calcium resonium can lead to severe constipation (unless appropriate laxatives are prescribed) and is therefore not used for routine control of plasma potassium levels. Newer medications have been reviewed and approved for use by NICE; sodium zirconium cyclosilicate (NICE TA599: 2019) and Patiromer (NICE TA623: 2020)

ANAEMIA

Anaemia due to kidney impairment can be diagnosed when GFR < 45 ml min⁻¹, i.e. CKD stage 3b, although it is more prevalent in stage 4 CKD (Mikhail et al. 2020). Haemoglobin levels of < 110g⁻¹ and low ferritin levels (with low to normal Hb) can impact on general nutritional status by causing general lethargy, taste changes, and a poor appetite; hence, it is always worth checking the patient's haemoglobin and ferritin levels if they present with these symptoms. Anaemia is also involved in the pathogenesis of left ventricular hypertrophy (LVH) and therefore increases the risk of CVD. A serum ferritin of <100 microgram l⁻¹ or a transferrin saturation of <20% indicates relative iron deficiency. It is important to ensure an adequate intake of iron, B₁₂, and folate and also vitamins B₆ and C, which all have important roles in erythropoiesis and the metabolism of haemoglobin. The consumption of foods which are high in iron (e.g. red meat, offal, and pulses) may be reduced in a kidney diet, particularly if protein- or phosphate-restricted diets have been prescribed and a potassium-lowering diet may result in decreased iron, folate, and vitamin C intakes.

If oral iron (Fe) supplements are used, 200–300 mg Fe day⁻¹ is required to restore iron status. These can cause side effects such as constipation and black stools. They can also interact with other medication, such as calcium-containing phosphate binders. In order to obtain a rapid improvement in iron status, intravenous preparations are more often used (NICE 2021).

ACIDOSIS

Metabolic acidosis is a feature of CKD and has a detrimental effect on muscle and bone metabolism. Recent guidelines suggest that bicarbonate levels are normalised using oral sodium bicarbonate for adults with GFR <30 ml min⁻¹ and serum bicarb < 20 mmol l⁻¹ (KDIGO 2012; NICE NG203: 2021). Another method of reducing acid load caused by dietary protein is to increase plant proteins (reduce animal proteins) and also increase fruits and vegetables (KDOQI 2020: nutrition guideline). This has a comparable effect to medication on raising bicarbonate levels and has additional heart and kidney health benefits (Melamed and Raphael 2021).

MALNUTRITION

The prevalence and risk of developing malnutrition is well documented in people with kidney disease; a meta-analysis of observational studies showed the prevalence was 11–54% in five studies of 1776 people in stage 4–5 CKD (Carrero et al. 2018). Irrespective of whether a therapeutic diet is recommended to treat any of the other problems listed above, all patients at CKD stages 4 and 5 should receive a dietary assessment and be screened for malnutrition at clinic review or on admission to hospital (Campbell 2013, Wright et al. 2019). A number of various screening tools are listed in the guideline by Wright et al. (2019), for example the renal iNUT for inpatients Jackson et al. (2019). The Malnutrition Universal Screening Tool (MUST). MUST is not felt to be sensitive or specific in those with kidney disease as it may not correctly identify oedema (which masks weight loss), nor does it identify the long-term suboptimal intakes which occur in people with kidney disease (Jackson et al. 2018). A patient with poor nutritional status at the start of dialysis will have a poor outcome in terms of survival, and therefore it is important to prevent malnutrition from occurring at the outset.

Regular dietary follow-up in clinic or by telephone should help to maintain optimal nutritional status by ensuring that a balanced diet is being achieved – that is, one that contains adequate macronutrients (protein, fat,

carbohydrate) and micronutrients (vitamins and minerals). If specific dietary reductions are advocated, it is important that the impact of these reductions on the intake of other nutrients, as well as the social effects, are fully evaluated. The diet should provide sufficient dietary freedom and enable the patient to lead a near-normal life. This means that dietary flexibility must be incorporated, and appropriate carers, relatives, or friends should be involved whilst educating the patient to promote maximum dietary adherence. A consensus statement on appropriate use of oral nutritional supplements gives a practical flow chart for the assessment of nutritional status and appropriate interventions in stages 4–5 CKD (Renal Nutrition Group 2015).

NUTRITIONAL ASSESSMENT

A full nutritional assessment includes collection of information from these six main categories:

- **Anthropometry:** This includes circumferences; mid-arm circumference (MAC), Mid-arm muscle circumference (MAMC), waist and hip circumference; BIA (bioelectrical impedance analysis), dual-energy X-ray absorptiometry (DEXA).
- **Biochemistry:** Levels of urea, creatinine, electrolytes, haemoglobin (Hb), albumin, and micronutrients are screened.
- **Clinical:** Comorbidities include systemic inflammatory diseases, non-functioning transplants, medication, and depression.
- **Dietary intake:** Examples are multiple 1-day food records and an estimation of requirements, assess dentition.
- **Environment:** These factors include social circumstances, health, and religious beliefs.
- **Function:** Physical function, activity levels; sit to stand, and grip strength are assessed.

UKKA guidelines recommend that patients with a GFR <30 ml min⁻¹ who are not on dialysis, should have a nutritional assessment screening at each outpatient visit

BODY COMPOSITION CHANGES

The K/DOQI (2003a) guidelines have indicated the need for more information regarding ‘the appropriate parameters to be used for assessment of body composition’. Nonetheless, simple ‘bedside’ measurements can indicate a decline in nutritional status as long as oedema and signs of fluid overload are identified. These include actual BW

(in comparison with IBW), weight loss of 5% in 3 months, and BMI < 20 kg m⁻² (NICE QS24: Nutrition support in adults 2012). The authors of the UKKA guideline 'Nutrition in CKD' also recommend use of the Subjective Global Assessment (SGA), where a grading of B/C on a three-point scale or a score of 1–5 on the seven-point scale indicate declining status and also bioimpedance (Wright et al. 2019).

Insufficient energy intake will lead to protein catabolism, which may present as muscle wasting. This can be detected using hand grip strength and other measures of physical function (sit to stand, shuttle test). MAMC can be estimated from measurements of MAC and triceps skinfold. Conditions that exacerbate protein/muscle loss include sarcopenia (muscle loss due to ageing), inflammation, acidosis, and lack of activity/exercise. Blood biochemistry may indicate whether there is inflammation (raised CRP, low albumin, raised white cell count) or acidosis (low bicarbonate levels) and if present, appropriate treatment should commence.

Where there is an energy deficit, fat stores will also be used to provide energy. This initially may not be a problem, particularly if the patient has excess body fat (overweight or obese), and can therefore mobilise these excess stores. The advantages of not having excess body fat include a decreased risk of CVD, hypertension, and diabetes. Formation of a fistula or insertion of a Tenckhoff catheter is also more difficult in patients who are overweight or obese. However, fat is used to insulate the body, to provide cushioning for bones, and (as just stated) to provide an energy source when food intake is poor. Recent evidence has shown that whereas being underweight increases mortality in patients on dialysis, being overweight may actually confer some advantage, at least in the first few years of dialysis (Friedman 2006). This is reflected in the KDOQI guidelines (Ikizler et al. 2020) that have stated that a BMI of up to 30 kg m⁻² is acceptable. The UKKA guidelines recommend a healthy BMI for those not requiring dialysis CKD of 18.5–26 kg m⁻² although haemodialysis recommendations are between 20–30 kg m⁻² (Baker et al. 2021).

CONCLUSIONS REGARDING NUTRITIONAL STATUS

Monitoring of nutritional status should start when advanced kidney care is required. Many renal departments hold multidisciplinary education sessions for patients to provide information on treatment options, diet, and support from social services. Ideally, an expert patient, a specialist kidney nurse, dietitian, social worker, and consultant should be involved in the sessions, with access to a psychologist if available. All patients should also receive

individual dietary advice, including assessing for vitamin and mineral status, and frequent monitoring is essential to accommodate any changes in kidney function. The Mediterranean or DASH diet together with lifestyle (activity and exercise) support may help reduce many of the long-term health problems we see in people with kidney disease and may also reduce the psychological and social burden of multiple dietary restrictions by instead promoting a healthy dietary pattern.

NEPHROTIC SYNDROME

Nephrotic syndrome (NS) is characterised by proteinuria >3 g day⁻¹, which results in hypoalbuminaemia and generalised oedema and is seen in glomerular diseases as well as diabetic nephropathy (KDIGO 2021). Hyperlipidaemia, clotting problems, and hypertension are also present. Loss of immunoglobulins and proteins that bind iron, copper, zinc, and vitamins A and D can result in an increased risk of infections and general malnutrition. The syndrome can arise in diseases that primarily cause glomerular damage such as focal segmental glomerulosclerosis (FSGS), membranous nephropathy (MN), and minimal change nephropathy (MCN) or secondary to other diseases, including diabetic nephropathy and autoimmune disease such as systemic lupus erythematosus (SLE). Treatment aims to control oedema, reduce proteinuria, and treat complications which arise including infections, hyperlipidaemia, and clotting problems. Diet therapy has a role to play in several of these areas (Table 12.1).

PROTEIN REDUCTION

Historically, in NS, a high-protein diet was advised with the aim of replacing protein losses. This is now thought to cause further damage to the glomerular basement membrane and exacerbate the proteinuria. An intake of 0.8–1 g protein kg⁻¹ IBW day⁻¹ is now recommended adding up to 1g per g of protein losses (up to 5g day⁻¹). This can result in reduced proteinuria, and improvements in other biochemical parameters such as phosphate, lipid, renin, and fibrinogen levels (thromboembolism is increased in NS: 10–30% of adult patients with NS may develop clotting problems). Not all studies have shown a corresponding increase in plasma albumin levels.

HYPERLIPIDAEMIA

The incidence of myocardial infarction has been reported as five to six times greater in NS compared with normal. Increased liver synthesis of lipoproteins and

Table 12.1 Management of nephrotic syndrome (NS).

Symptom	Dietary management
Hypertension and oedema	Dietary sodium reduction: 80–100 mmol day ⁻¹ . Fluid reductions may also be necessary, depending on the response to medication. Target weight loss 0.5–1 kg day ⁻¹ . ACE inhibitors commonly used (monitor potassium levels).
Proteinuria/hypo-albuminaemia	Moderate protein reduction: 0.8–1 g kg ⁻¹ IBW day ⁻¹ . Good control of blood glucose in people with diabetes. Medication can include steroids to treat the primary disease. ACE inhibitors also help to reduce proteinuria (monitor potassium levels).
Hyperlipidaemia	Standard lipid-lowering advice; <30% calories from fat, mono or poly unsaturated fat 7–10% calories. Statins and bile acid sequestrants.
Lower immunity	A balanced, nutritious diet will help prevent protein–energy malnutrition (PEM) and maintain micronutrient levels: monitor for signs of vitamin D deficiency and anaemia.

impaired metabolism of triglycerides results in raised triglycerides and cholesterol. Standard dietary lipid lowering advice can be given as well as the use of lipid lowering agents such as 5-hydroxy-methyl-glutaryl-coenzyme A (HMG-CoA) reductase inhibitors (statins) and bile acid sequestrers.

DIETARY MANAGEMENT: DIALYSIS

HISTORICAL REVIEW

Since the early 1990s, considerable progress has been made regarding modes and quality of treatment. Regular HD became available from the mid-1960s onwards when patients were initially selected for treatment, so were usually young and free from concomitant disease. Dietary management was aimed at controlling the patient’s fluid balance and biochemistry. During these early days of dialysis, a strict diet (by present standards) was followed by many patients, which consisted of a daily intake of 50 g protein, 50 mmol sodium, 50 mmol potassium, 35 kcal kg⁻¹, and 300 ml fluid.

As the quality of dialysis treatment improved during the 1970 and 1980s, dietary reductions were relaxed to a daily

intake of 60 g protein, 60 mmol sodium, 60 mmol potassium, 2500–3000 kcal, and 300–500 ml fluid. Even this slightly more generous HD diet was nutritionally incomplete without the use of high-energy, low-electrolyte supplements, and several books were published during the following years to promote dietary education (Vennegoor 1992).

During the early 1980s, CAPD (continuous ambulatory peritoneal dialysis) became established as a new chronic dialysis technique, although it had been used since the 1960s for patients who were haemodynamically too unstable for HD. By the mid-1980s, the diet for both HD and PD was similar to that prescribed today: 1–1.2 g protein kg IBW⁻¹day⁻¹ for HD and 1.2–1.5 g protein kg IBW⁻¹day⁻¹ for PD (Vennegoor 1992).

CURRENT CONCEPTS OF DIETARY MANAGEMENT FOR PEOPLE RECEIVING DIALYSIS

Specific dietary requirements will need adjusting when the mode of therapy (HD, PD, or transplantation) commences or changes. Current recommendations for dietary requirements are shown in Table 12.2.

PROTEIN

During HD, approximately 6–12 g of amino acids is lost per session. For PD, 8–12 g protein, in addition to 3 g amino acids, is lost per day. On the basis of these figures alone the additional dietary protein required to replace these losses can be calculated as 0.1 g kg⁻¹day⁻¹ for patients on HD and 0.2 g kg⁻¹day⁻¹ for patients on PD. Some authors have argued that, as the minimum safe protein intake for healthy individuals (and in the pre-dialysis phase) is approximately 0.75 g kg⁻¹day⁻¹, the recommended minimum intake on dialysis should be as follows: 0.9 g kg⁻¹day⁻¹ for HD and 1 g kg⁻¹day⁻¹ for PD. These are slightly lower levels than those recorded in Table 12.2 and, for *some* patients who are metabolically stable (i.e. not catabolic), nitrogen balance studies have shown that intakes at this level can be sufficient. As with any patient, in order to ensure that they are not becoming malnourished, it is important to measure nutritional status using a number of different methods such as those used in SGA (McCann 1996). See Appendix 12.B.

ENERGY REQUIREMENTS

A resting energy expenditure of 23 (19–25) kcal kg⁻¹day⁻¹ for HD and 24 (1925) kcal kg⁻¹day⁻¹ for PD is recommended to maintain nitrogen (protein) balance in patients on HD

Table 12.2 Dietary recommendations for patients undergoing kidney replacement therapy (KRT).

	HD	PD	TXP
Protein (g kg ⁻¹ IBW)	1.1–1.4 ^a	1.0–1.2 ^a	EAR
Energy (kcal kg ⁻¹ IBW)	30–40 (depending on age and activity)	30–40 (depending on age and activity)	EAR
Na (mmol day ⁻¹) ^b	80–100	80–100	80–110
K (mmol kg ⁻¹ IBW)	1.0	1.0–1.3	Free
P (mmol day ⁻¹) ^c	31–45 (26–32)	31–45 (26–32)	Free
Vitamins	Yes	Yes	Not required
Phosphate binders	Yes	Yes	Not required

Notes: HD, haemodialysis; PD, peritoneal dialysis; TXP, transplantation; IBW, ideal body weight; EAR, estimated average recommendations (national agreement).

^a Protein and energy intake for HD and PD based on Renal Association guidelines (Wright et al. 2019) and (Naylor et al. 2013).

^b 80–110 mmol equals 1800–2500 mg sodium.

^c Adjusting for protein requirement, i.e. 0.32–0.6 mmol phosphate g⁻¹ protein.

Source: Sodium, potassium and phosphorus intake for HD and PD based on EDTNA/ERCA and EBPg nutritional guidelines.

and PD. In order to calculate energy requirements an addition factor for physical activity and diet induced thermogenesis has to be included – for example, 1–1.1 (in bed and immobile), 1.1–1.2 (in bed/ sitting out), 1.2–1.25 (limited mobility) 1.25–1.4 (sedentary). For sedentary and older patients, 30–35 kcal kg⁻¹ IBW is usually sufficient. Underweight patients may need additional calories (and supporting micro-nutrients) to encourage weight gain, whilst overweight patients may need a calorie adjustment to encourage weight loss if appropriate (Todorovic and Mafrić 2018; Wright et al. 2019).

Dextrose (glucose) is used as an osmotic agent in PD for the removal of fluid. Up to 70% of this glucose is absorbed through the peritoneum, and this can exacerbate hyperglycaemia, hyperlipidaemia, and obesity. The amount of glucose absorbed increases as the osmotic strength of the dialysate increases. When calculating energy requirements for patients on PD, the glucose (and hence calories) absorbed from the dialysate needs to be included in the calculation. Glucose absorption may provide approximately 70 kcal for a 2l 1.36% exchange, 130 kcal for a 2l 2.5% exchange, and 200 kcal for a 2l 3.86% exchange. Daily intake from this source could be between 100 and 300 g glucose (400–1200 kcal), depending on the strength and size of the exchanges used and may be one of the factors that leads to an increase in central obesity and associated metabolic changes in PD patients. Recent PD guidelines discourage the use of the higher glucose solutions and suggest the use of glucose polymers or amino acid-containing solutions (Woodrow et al. 2017). Icodextrin is a PD solution which contains glucose polymers with a larger molecular

weight than glucose and is an effective osmotic agent. The calorie uptake is only half that of a comparable 3.86% exchange whilst achieving the same level of ultrafiltration. Some improvements in glycaemic control have been measured in patients who have diabetes, using one icodextrin exchange per day. See Chapter 9 for more information.

Overall, the diet should be aiming to promote cardiovascular health with an appropriate weight (BMI). The UK and US (Institute of Medicine) guidelines broadly agree with macronutrient content of the diet: Fat 20–30% of calories, linoleic acid (w6 PUFAs) 5–10% of calories, alpha linolenic acid ALA (w3 PUFAs) 0.6–1.2% calories. Heart UK suggests eating plenty of fruits, vegetables, and plant-based foods, along with a variety of healthy protein sources – beans, lentils, fish, nuts, seeds and poultry, lean red meat (watch quantity).

To meet ALA requirements means eating oily (fatty) fish twice a week. Additionally, the DOQI nutrition guidelines (2020) suggest there is evidence that omega 3 supplements can decrease triglycerides and LDL cholesterol levels and increase HDL; therefore, 1.3–4g/day long chain omega 3 PUFA may be prescribed for patients needing HD and it is reasonable to consider prescribing these for people having PD. Other advice includes to eat; high fibre cereals, low fat dairy foods, some healthy fats (vegetable oils), fewer foods and drinks high in sugar. Due to the potassium content of fruit and vegetables, for a person on haemodialysis this might mean choosing lower potassium options, but a working party of the European Renal Association-European Dialysis Transplant Association proposed the Mediterranean diet ‘as the diet of choice for patients with

chronic kidney disease (Chauveau et al. 2018). The main aims of the UKKA guideline are to promote a healthy weight, improved physical function, and a healthy heart. UKKA recommends maintaining 150 minutes a week of moderate-intensity exercise (Baker et al. 2021).

SODIUM AND FLUID

Once a patient becomes oliguric and eventually anuric, the intake of salt and fluid will need to be reduced to control interdialytic weight gain (IDWG) with HD and fluid balance with PD. Excessive IDWG in patients on HD contributes to hypertension prior to HD treatments, necessitating antihypertensive medication.

A reduced fluid allowance is probably the most difficult part of the dialysis diet to cope with. Up to 86% of patients may exceed an IDWG guideline of 1.5 kg day⁻¹ and there appears to be no difference between those who have diabetes and those who do not. Some groups of patients with different ethnic backgrounds appear to have additional problems with IDWG. Indo-Asian patients in particular may often be unable to adhere to their fluid allowances and this is attributed to a higher fluid and salt content of traditional foods and meals (de Brito-Ashurst et al. 2011).

Most renal centres in the United Kingdom regard an IDWG of 1.5–2.0 kg as acceptable. Considering the differences in size of patients, it may be more appropriate to base IDWG on dry weight using 4–4.5% as an acceptable IDWG (European Best Practice Guidelines, EBPg 2007). However, an upper limit is recommended for patients with BMI > 25 kg m⁻².

Sodium intake: the mechanism of thirst

It is important to remember what causes thirst. The sodium level in the body is finely tuned in healthy individuals as well as those with kidney disease. Too much dietary salt will cause the plasma sodium level to rise (transiently) and the thirst mechanism in the brain to act. It is then necessary to drink sufficient fluid to normalise the sodium level.

A sodium intake of 80–110 mmol day⁻¹ can help control thirst. This can be achieved by following the advice listed in the earlier section on hypertension.

Excessive IDWG may not always be due to poor understanding of dietary advice. Even 'solid' food contains some fluid and patients with a good appetite will have higher IDWG; this can be established with a detailed dietary assessment, indicating a high protein and energy intake.

Fluid includes anything liquid at room temperature (apart from vegetable oils) and also includes jelly, ice

cream, ice cubes, gravy, soups, sauces, and custard. A daily fluid allowance of 500–750 ml in addition to the average daily urine output is usually sufficient to prevent excess IDWG in patients on HD. UKKA guidelines suggest people on PD should have a minimum ultrafiltration of 750 ml which would suggest their fluid 'allowance' could be equivalent to 750 ml+PDUO (Woodrow et al. 2017). This amount may be modified depending on the actual level of ultrafiltration which is achieved with the lower strength exchanges of PD fluid.

Guidelines on fluid intake

The following additional tips can help the patient keep to their fluid allowance:

- Measure the daily fluid allowance in a water jug: Take out the equivalent amount after having a drink or if food with a significant amount of fluid is eaten.
- Divide the fluid allowance throughout the day.
- Use a small cup or glass instead of a mug or large glass.
- Drink only half a cup each time if possible.
- Ice cubes may be more thirst quenching, but each cube contains 30 ml fluid (2 tablespoons): lemon juice or other flavourings can be added.
- Rinse the mouth with water; gargle but do not swallow.
- Stimulate saliva production by sucking a piece of lemon or grapefruit, sherbets, or chewing gum.
- Try artificial saliva sprays.
- Take medicines with meals unless contraindicated.
- When going out, save the allowance of fluid to allow for an extra drink when socialising.
- Daily weight check in the morning before breakfast will reveal the rate of fluid accumulation in between HD treatments and the fluid status on PD.

POTASSIUM

Some patients starting dialysis continue to pass some urine. This helps to some extent with the excretion of sodium, potassium, and, of course, fluid. However, the urine is often described as 'poor quality' in that the level of these solutes are lower than usual and plasma potassium levels should be monitored closely. The risk of hyperkalaemia is greater in patients who do not pass urine. The dietary intake of potassium should be reduced to approximately 1 mmol kg⁻¹ IBW⁻¹ day⁻¹ for patients on HD to achieve a

pre-dialysis potassium level of 4–6 mmol l⁻¹. Hyperkalaemia can be a frequent problem, especially on HD, and dietary indiscretion is sometimes partly to blame, although the amount of potassium removed during dialysis can vary by as much as 70%. Patients having PD may have a more relaxed dietary potassium reduction, as potassium is constantly removed with PD and hypokalaemia has even been observed.

A detailed diet history should be taken for all patients so that the main sources of potassium in the patient's diet are known and the level of reduction and dietary advice given is based on a risk assessment of their usual dietary intake, urine output, and plasma potassium levels. Other reasons for hyperkalaemia should be investigated simultaneously as previously described. Some patients on HD consume foods with high potassium content during the first couple of hours on dialysis. However, the transit of food and fluid through the gastrointestinal tract may be slower whilst the patient is dialysing and so it is advisable to put a limit on this consumption as the potassium may not be completely removed.

PHOSPHORUS

The recommended intake varies from 1000 to 1400 mg (31–45 mmol day⁻¹), or approximately 0.5–0.6 mmol phosphorus per gram of protein up to 45 mmol day⁻¹. However, some guidelines (EBPG 2007) are stricter than the previous nutritional guidelines as they suggest a maximum of 0.4 mmol phosphorus per gram of protein per day. It is recognised that with higher protein recommendations, the phosphorus intake also increases, and there has to be a balance between reductions which prevent hyperphosphataemia and preserving an adequate and acceptable diet for the patient to follow (Lynch et al. 2011). Recent evidence has shown that plant-based phosphorus was associated with lower mortality in adults on haemodialysis and dietary advice will start to evolve as we understand more about the availability of phosphorus from different sources (Byrne et al. 2021; Su et al. 2022). Close collaboration of the multi-disciplinary team is required to prevent hyperphosphataemia. A combination of achieving an adequate dialysis prescription, phosphate binders which are acceptable to the patient and taken at the right dose at the right time, and clear dietary messages have been shown to improve phosphate biochemistry (Yokum et al. 2008; Caldeira et al. 2011; Gonzalez-Parra et al. 2012) although long-term improvements on mineral and bone disorders require larger, well-designed RCTs (randomised controlled trials) (Liu et al. 2015). For patients receiving dialysis, phosphate levels should be maintained or lowered towards the normal range.

VITAMINS AND MINERALS

During dialysis, the small molecules, such as water-soluble vitamins, are removed; losses are even higher with high-flux HD. The fat-soluble vitamin A is a larger molecule and vitamin A metabolites are therefore more difficult to remove and could lead to toxicity. However, with a functioning kidney there are also vitamin losses and so the question is whether dialysis removes greater amounts of vitamins than would normally occur. Evidence of vitamins at risk includes thiamin (B₁) in PD patients, pyridoxine (B₆) and ascorbic acid (vitamin C) in PD and HD, and folate in HD (Jankowska et al. 2017). To reduce cardiovascular risk, UK RA guidelines recommend monitoring folate and B₁₂ every 3 months if patients remain anaemic. Ascorbic acid is easily dialysed in both HD and PD. A high-dose vitamin C supplement should be avoided to prevent hyperoxalosis; 60 mg may be sufficient with a normal dietary vitamin C intake, while a supplement of 500 mg vitamin C may increase serum oxalate levels. Oxalate deposits as crystals in soft tissues such as muscle tissue and vital organs, and may increase the risk of myocardial infarction, muscle weakness, and bone disease.

The results of the Dialysis Outcomes and Practice Patterns Study (DOPPS) showed that water-soluble vitamin supplementation is associated with a 15% decrease in mortality (Fissell et al. 2004). At the time of the study, only 3.4% of patients from the UK kidney units were receiving water-soluble vitamins compared with 72% in the US. Current UKKA guidelines (Wright et al. 2019) suggest that 'water soluble vitamins be offered to dialysis patients with a reduced nutrient intake or those that have high solute clearance (daily or overnight dialysis)'. Table 12.3 lists the suggested daily recommendations in the United Kingdom and Europe (EBPG 2007).

Early reviews identified that deficiencies of iron, zinc, copper, manganese, and chromium are most likely to occur as a result of dietary changes, drug nutrient interactions, and protein losses (Wolk 1993; Rocco and Makoff 1997). The EBPG guidelines (EBPG 2007) and KDOQI nutrition guidelines (2020) do not recommend routine zinc or selenium supplements, but note that if symptoms of these deficiencies are detected (including thyroid dysfunction due to low selenium) then a 3- to 6-month trial is warranted.

MALNUTRITION

Malnutrition is a complication of HD and PD, and its consequences have been well documented since these techniques became available. A meta-analysis of 90 studies,

Table 12.3 Suggested daily dosage of vitamins for patients with ERF (EBPG and UK guidelines).

Vitamins	EBPG	RNI (UK)
Vitamin A	0	600–700µg
Vitamin E	400–800 (0) iu	no DRV given
Vitamin B1	1.1–1.2 (1.5) mg	0.8–1 mg
Vitamin B2	1.1–1.3 (1.7) mg	1.1–1.3mg
Vitamin B ₆	10 (10) mg	1.2–1.4mg
Vitamin B ₁₂	2.4 (6) µg	1.5µg
Folic acid	1000 (800–1000) µg	200µg
Pantothenic acid	5 (10) mg	no DRV given
Niacin	14–16 (20) mg	13–17mg
Biotin	30 (300) µg	>10µg
Vitamin C	75–90 (60) mg	40mg

Notes: RNI, recommended daily intake. Dietary reference values (DRV) for food energy and nutrients for the United Kingdom.

including 16,434 dialysis patients, showed a prevalence of malnutrition of 28–54% (increasing to 98% in PD patients and 81% in HD patients) (Carrero et al. 2018). The use of different methods to determine the extent of malnutrition has led to some differences in the stated prevalence. British Association for Parenteral and Enteral Nutrition (BAPEN) (a charitable association that raises awareness of malnutrition and works to advance the nutritional care of patients) has been coordinating the use of MUST in UK hospitals. The annual audit has indicated that the prevalence of malnutrition in renal inpatients is 30%. However, using other scoring systems the prevalence has been much higher at 64–90%. The issue lies with the sensitivity and specificity of MUST. When MUST was compared with SGA in 64 patients on HD, the sensitivity was 31% and the specificity was 95%; that is, it had poor ability to detect ‘true cases’ of malnutrition (Fisher et al. 2010, Jackson et al. 2018).

Effects of malnutrition are:

- failure to thrive;
- increased morbidity;
- delayed wound healing;
- decreased resistance to infection;
- electrolyte imbalance;
- prolonged hospitalisation;
- muscle wasting (skeletal muscle as well as heart/lung, etc.);
- loss of protective subcutaneous fat;

- lethargy/apathy;
- increased mortality.

PROTEIN ENERGY WASTING

An expert working party convened by the International Society of Renal Nutrition and Metabolism (ISNMRD) attempted to simplify the nomenclature used to describe malnutrition in kidney disease (Fouque et al. 2008), and this has been updated more recently (Obi et al. 2015). The term they feel encompasses the changes indicating decreased nutritional status is *protein energy wasting* (PEW). They define this as a ‘state of decreased body stores of protein and energy fuels’ which is ‘often associated with diminished functional capacity’. It includes syndromes such as MIA, but they emphasise that PEW, as can be seen from the list below, is not just due to an inflammatory component (although it is estimated that up to 50% of patients with kidney disease show evidence of an ongoing inflammatory response).

CAUSES OF MALNUTRITION

There are several overarching reasons for malnutrition in patients on dialysis, and these are multifactorial in origin (Obi et al. 2015):

- reduced dietary intake:
 - reduced appetite;
 - existing malnutrition at the start of dialysis due to uraemia or unsupervised pre-dialysis dietary restriction;
 - conflicting dietary recommendations (e.g. increasing protein whilst decreasing the intake of phosphorus);
 - dietary recommendations which decrease palatability of food: decreased salt intake, decreased fat or sugar intake;
 - coexisting gastrointestinal disease (i.e. gastroparesis) or other comorbidities such as cardiac failure, cancer, stroke;
 - multipharmacy prescriptions;
 - inadequate provision of nutrients in food provided by hospitals or nursing homes;
 - financial constraints;
 - decreased physical ability (shopping, cooking);
- reduced appetite;
 - raised cytokines; TNFα;
 - inadequate dialysis leading to uraemia;

- suppression of appetite due to PD; this may be due to glucose absorption, abdominal pressure from the dialysate fluid, or constipation;
- anaemia or other micronutrient deficiencies; zinc, B vitamins;
- old age; taste, sight changes;
- depression;
- increased nutritional losses;
 - losses during dialysis: vitamins, minerals, proteins, and amino acids;
 - persistent proteinuria;
 - protein loss during peritonitis;
- altered metabolism;
 - inflammatory response as a result of the dialysis process; the presence of inflammatory cytokines results in appetite loss, muscle breakdown, and low albumin;
 - untreated acidosis: impaired muscle and bone metabolism;
 - inadequate dialysis: buildup of waste products and cytokines;
 - low physical activity: low anabolic stimulation of muscle and bone;
 - intercurrent illness/infections, causing raised requirements, increased cytokines;
 - hyperparathyroidism: impaired muscle and bone metabolism;
 - resistance to insulin, growth hormone, and insulin-like growth factor;
 - low 'active' vitamin D: impaired muscle and bone metabolism.

Comorbidities and drug nutrient interactions also have an impact on all of these four main points.

DETECTION OF MALNUTRITION

As discussed previously, the detection of malnutrition should involve monitoring a number of components: anthropometry, biochemistry, clinical, diet, and exercise/activity. Many screening tools only include two of these components. For example the Malnutrition Universal Screening Tool incorporates anthropometry (weight, weight change) and diet. SGA includes anthropometry,

clinical, diet, and exercise/activity although adapted versions have also included measurement of biochemistry (Kalantar-Zadeh et al. 2001).

Assessing nutritional status

Whichever methods of assessment are used to assess nutritional status, they should be done regularly and systematically for all patients as physical deterioration can occur rapidly and is difficult to reverse (Engel et al. 1995). It is important to identify malnutrition so early rehabilitation and improved clinical outcomes are possible. NICE guidelines (CG32 updated QS24 2012), recommended that 'All hospital in-patients on admission and out-patients at first appointment should be screened for presence or risk of malnutrition'. Screening should take place weekly for in-patients, and within a month of starting dialysis for out-patients and every 2–3 months for stable HD patients or 'earlier if their clinical condition changes'. A monthly MDT review of blood results and dialysis nurse vigilance for changes in dry weight and oedema are crucial for monitoring patient health. Several screening tools have been developed by kidney teams and are listed in the UKKA guidelines (Wright et al. 2019).

Methods of dietary assessment

Methods of dietary assessment include:

- *Twenty-four-hour recall*. This is quick and assesses recent intake.
- *Three-day food diary*. This can include a weekend day and one HD day and gives a better illustration of the variety of foods eaten. It may also reveal the disruption to meal times caused by a dialysis day – for HD patients significant decreases in all nutrients can occur 3 out of 7 days.

TECHNIQUES TO ASSESS BODY COMPOSITION

The best-known techniques are:

- *Height and weight (BMI), percentage weight loss over time*. The minimum data set and diagnostic criteria for malnutrition recommended by the RA include: BMI < 20 kg m⁻², actual BW < 85% ideal weight, unintentional oedema-free weight loss of 5% in 3 months or 10% in 6 months.² A minimum BMI of 23 kg m⁻² is recommended for dialysis patients (EBPG 2007).

² SGA is included in the minimum data set for all patients with CKD stages 4 and 5.

- *Mid-upper arm anthropometry.* MAC, tricep skinfold, MAMC. MAC is easy to perform, non-invasive, and training can reduce observer error repeatable to an acceptable degree. Skinfolts are more prone to observer error; a measure of muscle function may be a better way of assessing muscle mass (e.g. grip strength, sit-to-stand test or walking test). MAMC can be calculated from a measurement of MAC and the triceps skinfold.
- *Bioelectrical impedance.* Quick and non-invasive, but it is an indirect measure and it is influenced by hydration and electrode placement (Lindley et al. 2005). BIA measurement of phase angle may be helpful in determining hydration state. RA guidelines recommend that BIA and handgrip strength may be useful in those diagnosed at risk of or with malnutrition. A review of BIA technology by NICE also found some evidence that this technique can result in better fluid management compared to clinical judgement (NICE 2015) and is recommended in the UKKA Haemodialysis guidelines as an objective tool to assess fluid state (2019).
- *DEXA.* This measures bone mineral content and density. It relies on assumptions about hydration status which may not be valid in patients with kidney diseases, particularly for the measurement of lean body mass. However, DEXA is expensive and not usually available for routine clinical use.

BIOCHEMISTRY

It had always been assumed that serum albumin was a reliable marker of nutritional status, however this relationship has been questioned as other causes of low albumin are also common in kidney disease including fluid overload and inflammation (Friedman and Fadem 2010). As stated, a low albumin is certainly predictive of a poorer outcome and an important predictor of morbidity and mortality.

The correct diagnosis is crucial for appropriate medical management as there are several potential causes of hypoalbuminaemia:

- *Decreased synthesis due to poor nutritional intake.* Albumin has a half-life of 2–3 weeks, therefore complete starvation can take at least this length of time to make an impact on plasma levels. In ‘partial’ starvation, where patients are not quite meeting their requirements and are slowly losing weight, albumin levels can be maintained for months even when substantial amounts of weight are lost, due to adaptive mechanisms.
- *Decreased synthesis due to the acute phase response.* This is part of the body’s immune response to cell damage

which can arise through trauma, infection, or cancer. The cytokine IL6 is thought to be the mediator which instructs the liver to reduce production of certain proteins (albumin, transferrin) and increase production of others (CRP, ferritin). This interrelation between CRP and albumin may explain why a low albumin has been associated in so many studies with increased morbidity and mortality.

- *Inflammation.* The presence of inflammation can also cause the endothelium to become ‘leaky’, with the redistribution of albumin pools; for example, from vascular spaces to the intervascular space, which may have an impact on the efficacy of dialysis.
- *Albumin losses.* This is due to proteinuria, dialysis losses, or peritonitis.
- *Dilution.* If the patient is fluid overloaded, for example before a HD session, or if dry weight needs to be adjusted. For example, 3 l overload can dilute plasma albumin from 42 to 37 g l⁻¹.
- *Albumin assay methods vary.* It is important to use the same method of measurement each time (bromocresol green or bromocresol purple), or if comparing patients based at different kidney units.
- *Urea nitrogen.* Urea content of 24-hour urine samples in patients who do not need dialysis and urine plus dialysate collection in patients undergoing PD can be used to calculate urea nitrogen appearance. This is equivalent to dietary protein intake in nutritionally stable patients (PD dialysate collection can also be used to estimate protein losses).
- *Plasma urea measurements.* In patients receiving HD, changes in plasma urea measurements (collected for dialysis adequacy tests) can be used to calculate the protein catabolic rate (PCR). This is only equivalent to protein intake in patients who are nutritionally stable. Urinary urea also needs to be included in the calculation.

SUBJECTIVE GLOBAL ASSESSMENT

SGA is an assessment of nutritional status and was first performed with surgical patients (Detsky et al. 1987). It is based on patient history and physical examination. A simple questionnaire is usually completed by a trained nurse or dietitian. The Canada-USA (CANUSA) Peritoneal Dialysis Study Group showed the relative risk of death on PD increased with age, insulin-independent diabetes mellitus, CVD, low serum albumin, and worsening nutritional

status. Malnutrition (identified by SGA) correlated strongly with an increase in number of days hospitalised (CANUSA Peritoneal Dialysis Study Group 1996).

PATIENT HISTORY

The history includes weight changes, dietary intake, gastrointestinal symptoms, and functional status and can include comorbid disease.

PHYSICAL EXAMINATION

Physical examination takes into account loss of subcutaneous fat, muscle wasting, oedema, and ascites. Each section is rated on a three- or seven-point scale by the interviewer. An overall score is then assigned depending on the severity of symptoms. For the three-point scoring system subjects are given a score of A, B, or C: A for well nourished, B for mild-moderate malnutrition, and C for severe malnutrition. The seven-point score subdivides these categories into: A, A-, B+, B, B-, C+, C, or sometimes a numerical score is used: SGA scores of 6–7 (well nourished), 3–5 (mild-moderate undernutrition), and 1–2 (severe undernutrition) (Appendix 12.B).

The seven-point SGA was developed for the CANUSA study (Churchill et al. 1996) and was found to positively correlate with BMI, percentage body fat, and MAMC (Visser et al. 1999). A 1-unit lower SGA score was associated with a 25% increase in the relative risk of death and a 1-unit increase in score was associated with reduction in days hospitalised. Reproducibility was good: 81–91% when two observers were compared. A prospective longitudinal study of 1600 patients concluded that SGA could distinguish different degrees of PEW and confirmed that a greater degree of PEW was associated with increased mortality (de Mutsert et al. 2009).

K/DOQI Guidelines (K/DOQI 2000) stated that 'SGA is a valid and clinically useful measure of protein-energy nutrition status in maintenance dialysis patients'. The UK RA and EBPG (2007) also supports the use of the three- or seven-point SGA.

PROTEIN ENERGY WASTING

Measures are recommended to diagnose PEW (Hanna et al. 2020) include:

- Serum chemistry: albumin, prealbumin.
- BMI: body mass $<23\text{kg/m}^2$: unintentional weight loss 5% over 3 months or 10% over 6 months, total body fat percentage $<10\%$.

- Muscle mass loss: 5% over 3 months or 10% over 6 months, reduced MAMC by 10% in relation to 50th percentile; lower than expected creatinine.
- Deficient dietary intake: 0.8g/kg/d protein intake for 2 months in dialysis patients, $< 25\text{ kcal/kg /d}$ energy intake for 2 months.

They acknowledged that, whilst nutritional scoring systems such as SGA or malnutrition inflammation score will to some extent identify PEW, there needs to be more focus on how to prevent and treat muscle mass loss and cachexia.

TREATMENT OF MALNUTRITION

A thorough assessment should identify the nutritional state of the patient and any modifiable causes of deterioration. This is the diagnosis stage in the Dietetic (Nutrition) Care Process outlined by the British (American) Dietetic Association and is illustrated with respect to patients with kidney disease (Memmer 2013). Although there are usually several possible causes and potential treatments (Carrero et al. 2013; Ikizler 2013; Ikizler et al. 2013), a protocol should be in place so that an initial intervention can be started immediately, e.g., iNUT (Jackson et al. 2018), which describes the actions to be taken for each level of malnutrition. This may require nursing staff to start monitoring the patient using food charts or to start appropriate supplements (suitable for patients with kidney disease) in the first instance and alert the kidney dietitian. The dietitian will carry out a full nutritional assessment; however, identifying and targeting the multiple barriers to achieving good nutritional status requires a team approach and the correct interventions and care plan can result in improvements in several nutritional parameters.

The primary aim of nutrition support is for patients to meet their nutritional requirements (macro- and micro-nutrients) in the least invasive, most effective way. The patient's protein and energy intake can be calculated from food intake charts, or a 24-hour recall and the nutrient deficit can be calculated using a very simple formula:

$$\text{requirements} - \text{current intake} = \text{nutrient deficit}$$

This deficit can be met using the following methods of nutrition support:

- Oral. For patients who are able to eat and drink normally, fortified foods or foods with a high nutrient content or sip feeds; support and encouragement with eating if necessary.

- Nasogastric or gastrostomy feeding for patients who are unable or unwilling to eat or drink normally. Oral and tube feeding can be combined (e.g. tube feeding overnight, whilst the patient sleeps, and encouraging normal eating/ drinking during the day).
- Intraperitoneal amino acids (IPAA) with PD.
- Intradialytic parenteral nutrition (IDPN) during HD.
- Total parenteral nutrition (TPN) can be administered for patients whose gastrointestinal tract is not functioning sufficiently.

Nutrition support is ineffective without close teamwork and each member of staff agreeing to carry out specific roles. All healthcare workers directly involved in inpatient care should receive training in the following (National Institute for Health and Clinical Excellence 2006a):

- the importance of nutrition;
- the correct use of appropriate screening tools and indications for nutrition support and delivery;
- when and where to seek advice on nutrition support.

Oral nutritional support

There are two key stages in providing oral nutritional support (ONS):

1. Identify any barriers preventing the patients from meeting their requirements and referral to other specialists, if necessary.
2. Involve the patient in deciding which type of supplementation is appropriate.

Barriers to meeting requirements

Gastrointestinal problems should be identified by a nutrition screening tool. If chewing and/or swallowing are a problem, the consistency of food may need to be modified. If the patient is an in-patient the catering department will have to be notified and it may be appropriate to refer to the speech-and-language therapist. People who lose weight rapidly often find that their dentures no longer fit properly; however, this problem cannot usually be remedied during the patient's stay. Thrush infections are common in undernourished patients or patients who are prescribed immunosuppressants. This can cause a sore mouth, taste changes, and swallowing problems and can be relatively easily treated with antifungal agents. Constipation and diarrhoea are equally deleterious to the patient's appetite and need to be identified and treated.

Motivating and encouraging the patient at mealtimes is often necessary and needs to be supervised by a member of the nursing team. Actively involving older people in their nutritional care and allocating a nurse to oversee their nutritional needs can improve intake by 30% (Pederson 2005). If active depression is an underlying cause, it may be useful to involve the help of a counsellor/psychologist.

Prior to admission, the patient may have had a long period of deterioration due to the lack of ability or facilities to cook and shop. These problems may be resolved by a social worker and involvement of other family members or friends. If physical weakness is a problem, a physiotherapist or occupational therapist can suggest exercises to strengthen the patient or tools to assist the patient.

In hospital, physical weakness may prevent the patient cutting up their food or removing packaging. Poor vision may also be a problem. Assistance must be provided when these problems are identified. Loss of muscle mass is one of the main consequences of malnutrition and, in elderly people in particular, this leads to decreased capacity for the activities of daily living, loss of independence, and decline in mental status.

Physical activity and physiotherapy can improve muscle mass and should be part of nutrition support in the elderly patient (Suetta et al. 2004). Studies in patients on dialysis have shown improvements in muscle fibre and general muscle structure, as well as exercise capacity, after a training programme has been initiated (Kopple et al. 2005; Heiwe and Jacobson 2011; Koufaki et al. 2015). However, other authors have found a disappointing response to resistance exercise training (Ikizler 2011) and it may be that acidosis, which is prevalent in patients with kidney disease, actually worsens during exercise, thus preventing a more positive outcome (Clapp and Bevington 2011). Nonetheless, both UK and European guidelines promote physical activity in patients undergoing dialysis and recommend that patients should be given the opportunity to participate in regular exercise programmes (EBPG 2007; Baker et al. 2021).

Food supplementation including nutritional supplements

This may involve providing fortified foods, snacks, or drinks with high nutritional content. Some of these can be given between meals so that the patient can eat little and often. Examples of these foods include sweet biscuits, cakes, cheese and biscuits, yoghurt, and mousses (<https://www.malnutritionpathway.co.uk/resources>).

Supplement drinks, mousses, and soups are available as well as protein and energy powders and liquids, although

the latter are more likely to be added during food preparation. In order to metabolise protein and energy supplements efficiently, the full range of micronutrients are required and an appropriate multivitamin and mineral supplement may be also given. The supplement drinks and desserts should be prescribed as a medicine, and their listing on the drug chart may help improve distribution and monitoring of intake. The drinks may be milkshakes, juice drinks, or yoghurt drinks. The flavours can include various fruits, vanilla, chocolate, neutral, and savoury. Mousses and bars are available and may be useful for patients with reduced fluid allowances. Low-electrolyte, low-fluid supplements and feeds, and multivitamin supplements have been developed for patients who have kidney disease. Even these adapted nutrition support regimens may not result in the best possible outcomes because they do not supply enough of the relevant nutrients as mentioned in the case studies below, or they may even add to the burden of nutrients which cannot be efficiently utilised at the time. Two systematic reviews Stratton et al. (2005) and Liu et al. (2018) supported the use of ONS in dialysis patients to improve serum albumin and BMI and a consensus statement is available for use of ONS in stages 4–5 CKD (MacLaughlin et al. 2015). More research was required to investigate other clinical end points (anthropometry, quality of life, physical function) and also to determine whether kidney-specific formulae had any advantage over standard feeds (Stratton et al. 2005).

The kidney dietitian will be aware of the nutritional content of any supplements as well as potassium and phosphate content. The ratio of protein to energy may vary, which may suit the needs of different patients. A malnourished patient's potassium and phosphate intakes are usually poor and they may even have low plasma levels; however, it is always necessary to be aware of the potassium content; powdered drinks which require the addition of milk may be unsuitably high in potassium. The patient may need to continue phosphate binders unless they are extremely malnourished or at risk of refeeding syndrome.

Nursing and/or catering staff need to ensure that the supplements/fortified foods are given to the patient at the right time, at the correct temperature, and that they are actually consumed by the patient.

Nasogastric and gastrostomy feeding

The systematic review by Stratton et al. (2005) also considered use of enteral feeds, although only two studies (non-RCTs) were found and both involved haemodialysis patients. The insertion of a gastrostomy feeding tube enables long-term tube feeding to be carried out without

the discomfort of a nasogastric (NG) feeding tube. NICE guidelines recommend gastrostomy placement if NG tube feeding is not appropriate or if feeding is likely to be required for more than 4 weeks. Surveys have shown that the majority of (non-renal) patients (83%) accepted the gastrostomy feeding well. Gastrostomy tubes may be placed via a percutaneous endoscopic method (PEG) or radiological method (RIG). Nonetheless, the cohort report on eight HD patients with a PEG feed (Sayce et al. 2000) concluded that there were few complications, and dry weight, MAC, and albumin all increased significantly.

Nutritional peritoneal dialysis

Dialysate containing 1.1% amino acid solution will provide a net gain of 18 g amino acids from one 2 l exchange. It is important to ensure that energy requirements are being met otherwise the aim of achieving a positive nitrogen balance will not be met. Studies have indicated an improvement in nitrogen balance with increases in albumin; the dialysate seems to be well tolerated (Taylor et al. 2002; Tjiong et al. 2005). Use of amino acid-containing dialysate will also reduce the overall amount of glucose absorbed during dialysis (Woodrow et al. 2017). The UK guidelines suggest that IPAA can be 'considered for selected cases when oral or enteral intake is suboptimal', which is similar to the DOQI Nutrition guidelines (2020). UK Guidelines for PD (Woodrow et al. 2017) also suggest IPAA can be used to optimize diabetic control.

Intradialytic parenteral nutrition

Parenteral formulas containing 50–70 g amino acids, and 1000 kcal from fat and carbohydrate, can be safely delivered via the venous return during the HD treatment. Glucose monitoring during treatment is essential to prevent hyperglycaemia, and fluid balance can be adjusted accordingly. An oral multivitamin and mineral supplement may be required to ensure efficient use of the protein and calories. The cost of IDPN is 10 times that of oral supplementation; therefore, the latter method should be encouraged first. Case reports have shown the good safety profile of this technique (Dukkipati et al. 2010), although patients must be monitored for refeeding syndrome, hyperglycaemia, and hypertriglyceridaemia. A systematic review only identified three RCTs comparing IDPN with alternative means of nutrition support and stated that there was insufficient evidence to demonstrate net benefit or harm (Sigrist et al. 2010; Ikizler et al. 2013). However, a recent RCT showed improved nutritional parameters in malnourished patients given IDPN compared with standard nutrition support (Marsen et al. 2017). In the United Kingdom, IDPN

is often used after alternative feeding methods have been tried (and failed) or discounted because of the burden it would place on the patient and their carer.

The latest UK guidelines (Wright et al. 2019), guideline 3.4, suggest that IDPN ‘may be considered for selected cases when oral or enteral intake is suboptimal’. This mirrors the evidence brief prepared by Anderson et al. (2018) and in the DOQI guidelines for Nutrition (DOQI 2020) that whilst it is ‘reasonable to consider use of IDPN in the dialysis population’ there was lack of evidence demonstrating superior effect of IDPN over enteral/ oral interventions. It could be argued (authors opinion) that IDPN is most effective when other routes have failed, and therefore randomised controlled trials are not applicable in this scenario.

Monitoring nutritional support

This may require daily recording of food intake charts and weighing the patient regularly. Food records are best completed as the meal is being finished in order to observe the patient and note any problems, as well as record the amount and type of food eaten. Patients can often forget what they have eaten within a couple of hours. Monitoring of biochemistry and fluid balance is also crucial for patients with kidney disease (very low as well as high levels of potassium and phosphate are possible) and most kidney units have computer systems that can identify values outside of the normal range and create an alert for action to be taken. Repeat assessments of nutritional status should occur within 1 month after starting dialysis (the first appointment should be made shortly after starting treatment or ideally when the patient is seen in a low clearance clinic at the start of discussions regarding kidney replacement therapy), and then repeated every 2–3 months for stable patients. Those identified as malnourished will be assessed much more frequently, e.g. dietary intake and oedema-free weight may be assessed weekly but other body composition measures may take longer to change; arm anthropometry such as MAC can be repeated monthly.

TRANSPLANTATION

Kidney transplantation is thought to offer the patient with AKD the best chance of rehabilitation and a good quality of life.

POST-OPERATIVE TRANSPLANT CARE

Appetite may initially be poor post-operatively and steroids can increase protein catabolism; therefore, both kidney and gastrointestinal function should be monitored.

The rate at which biochemistry and urine output return to normal can vary (sometimes within a couple of days after surgery, or it can take several weeks) and needs to be monitored closely. There may be an ‘oliguric stage’ where fluid and electrolyte reductions are still required. This can progress to a polyuric stage, where intravenous support may be necessary to prevent fluid and electrolyte levels dropping below normal; dehydration at this stage can damage the new kidney. Nutritional requirements and the need for nutrition support can be assessed as previously described. Uncomplicated surgery increases metabolic rate by 5–20%, and this should be included in the protein and energy requirements. The review by Fong and Moore (2018) quoted protein recommendations, in the immediate post-operative period, 1.3–2g protein kg⁻¹ body weight day⁻¹.

LONG-TERM POST-TRANSPLANT CARE

The advice given to patients should include healthy eating (with some advice on food hygiene), exercise, ideal body weight < 25 kg m⁻² and avoidance of smoking, excess alcohol intake, and exposure to too much sun (Baker et al. 2017). One of the positive aspects of transplantation is that the dietary changes are usually relaxed; however, it is necessary to reinforce advice on healthy eating to help reduce the risk of obesity, CVD, diabetes, and also cancer.

Nutrient requirements are based on recommendations for the general population. The ‘Eat Well Guide’ is an appropriate model on which to base nutritional advice and meal suggestions (NHS 2022).

CARDIOVASCULAR DISEASE

CVD is the cause of 60% of deaths in transplanted patients and the incidence of CVD is five times greater than expected for age and gender. The main risk factors are obesity, hypertension, hyperlipidaemia, diabetes, sedentary lifestyle, and smoking.

Prevalence of CVD risk factors are as follows:

- Elevated levels of serum triglyceride and cholesterol are found in 36% and 63%, of transplant patients, respectively.
- Arterial hypertension is present in 60–85% of patients.
- Post-transplant diabetes affects 4–18% of patients.
- 60% may gain weight, with 30% showing an increase of 10% from baseline (Cashion et al. 2014) and 63–77% were overweight at one year (Baum et al. 2002).

- Odds ratios for post-transplant diabetes were 3.5 and 5 times greater in Black and minority ethnic groups and obese recipients (Baum et al. 2002).

Excessive weight gain involving increased body fat leading to overweight and obesity associated with a raised waist circumference indicative of increased visceral fat is common with a successful transplant and is multifactorial:

- The patient's appetite increases due to increased feeling of well-being and release from dietary constraints. Relaxation of restrictions after transplant can lead to a more liberal intake of high-calorie foods such as dairy products, fried potato products, and chocolate.
- Steroids stimulate the patient's appetite and impair glucose tolerance.
- Activity and exercise levels may be low. Patients are often reluctant to exercise because of lack of confidence and low exercise tolerance owing to previous inactivity.
- The combination of an increased calorie intake and low activity levels leads to a rapid gain in body fat.

Obesity contributes to hypertension, hyperlipidaemia, and insulin resistance, and these in turn contribute to CVD and poorer long-term outcomes for graft survival. The patient should be made aware of the risk of obesity at an early stage, pre-transplant if appropriate. Patients with a BMI > 30 kg m⁻² prior to transplantation are advised to lose weight and post-transplant patients are advised to aim for a BMI < 25 kg m⁻² (Baker et al. 2017). Exercise is recommended prior to transplant as this may aid post-transplant recovery and also after transplant in line with current UK NHS guidelines (Baker et al. 2021). Target lipid levels are the same as the general population.

Control of calorie intake and increasing energy expenditure through activity and exercise are usually necessary. Additionally, poor eating habits may have formed whilst adhering to the dietary allowances on dialysis; intake of fruit and vegetables and other 'cardio-protective' foods, such as oily fish, are often low (very few patients have the recommended five portions of fruit and vegetable per day, or fish twice a week). Regular reinforcement of healthy eating advice can help reduce weight gain and improve some cardiovascular risk factors (Brown et al. 2020; Zelle et al. 2013).

BONE DISEASE

There may be some improvement in bone parameters post-transplantation but bone turnover abnormalities can persist, and vitamin D, calcitriol, alphacalcidol, and

antiresorptive agents may still be needed in the first year post-transplant (Burton et al. 2018). Improved lean body mass (muscle) and bone strength may result from diet and exercise advice. Patients with or at high-risk of developing osteoporosis may need to avoid steroids; DEXA scanning can be used to monitor the condition. The National Osteoporosis Guideline Group guidelines for steroid-induced osteoporosis are recommended (NOGG 2021). These guidelines discuss the importance of vitamin D (800 iu day⁻¹), calcium intake (700 mg day⁻¹), and weight-bearing exercise to improve bone health. They also discourage smoking, excess weight, and excess alcohol intake (≤2 units a day), which are also discussed in the RA Guidelines (Baker et al. 2017). NOGG (2021) and DOQI nutrition guideline (2020) also recommend vitamin D supplementation with cholecalciferol to correct 25 hydroxyvitamin D deficiency and the DOQI guideline suggests monitoring phosphorus level in transplant patients in case of high or low levels and treating accordingly.

DIABETES

The development of new-onset diabetes after transplantation (NODAT) is exacerbated by immunosuppressive agents: steroids, tacrolimus, and ciclosporin. People who are elderly, plus those of African-Caribbean, and Hispanic heritage are most at risk. Graft loss is four times greater for patients who have diabetes. Fasting blood glucose should be checked every 3 months in all non-diabetic transplanted patients. The CAVIAR study showed improvements in fat mass and a trend towards less diabetes post-transplant (7.6% vs. 15.5%) in 130 transplant recipients (who did not have diabetes) after 6 months of individualized behaviour change therapy, which included dietary advice and a graded exercise programme (Kuningas et al. 2023).

SUMMARY OF DIETARY ADVICE FOR KIDNEY TRANSPLANT RECIPIENTS

A practical guide suggests filling a plate: ½ with a mix of fruit and vegetables, ¼ with protein rich food, and ¼ with high fibre grain or starchy vegetable. Narrative reviews discuss the evidence for Mediterranean and DASH diets improving cardiovascular risk factors, reducing oxidative stress, and improving acid base balance and glomerular haemodynamics (Goldfarb et al. 2021):

- Monitor biochemistry and blood pressure control, in particular lipid levels (cholesterol and triglycerides), blood glucose, potassium, bone minerals, PTH, and haemoglobin.

- Aim for acceptable BMI: the 'Eat Well Guide' is an appropriate food model to use.
- Emphasise eating a variety of fruit and vegetables: aim for at least five portions per day.
- Encourage high-fibre foods (soluble and insoluble).
- Encourage fish, particularly oily fish, lean meats, and pulses.
- Use foods high in sugar, saturated fat, and salt sparingly.
- Dairy products should be low fat, with attention to meeting calcium requirements.
- Alcohol consumption should be within usual recommendations.
- Be aware of good food hygiene practices (Baker et al. 2017) and follow FSA food hygiene advice.
- Encourage physical activity and regular exercise.
- Avoid smoking and too much sun exposure.

Ideally, a team of specialists should be available to help with the rehabilitation of transplanted patients, including the dietitian, nurse, physiotherapist, social worker, and counsellor.

DIETARY MANAGEMENT IN PAEDIATRICS

CKD may be present after birth or later in life and can proceed to ESKD during childhood. Growth and neurodevelopment depend strongly on nutrition during early childhood and can be profoundly affected by CKD (Rodig et al. 2014; Wesseling-Perry & Salusky 2013). This is especially the case during infancy and in very young children where spontaneous nutritional intake can be poor (Foster et al. 2012). Abnormal changes in bone mineralisation of the growing skeleton, and early markers of cardiovascular disease, have been evidenced as early as CKD stage 2 (Wesseling-Perry et al. 2012; Mitsnefes, 2012). With evidence of suboptimal growth in up to 35–50% of children with CKD (Seikaly et al. 2007; Rodig et al. 2014; Fivush et al. 1998), this may affect their future education and employment prospects (Broyer et al. 2004; Rocha et al. 2011).

The factors contributing to growth and final adult height in those who require dialysis during childhood are multifactorial, predominantly driven by nutrition, metabolic and hormonal alterations, and comorbidities (Silverstein, 2018; Mekahli et al. 2010; Harambat et al. 2014). However, intensive feeding and early transplantation have been shown to achieve a mean adult height within the normal range in those without

comorbidities (Haffner & Zivicnjak, 2017; Mekahli et al. 2010), with an overall improvement in post-transplantation final adult heights over the past two decades (Harambat et al. 2014; Fine et al. 2010).

In order to optimise nutrition and growth, early nutritional intervention is essential and must be maintained on a long-term basis. Early nutritional assessment should include the regular monitoring of growth (weight, height, and head circumference) and dietary analysis by means of food diaries or dietary recall (Nelms et al. 2021). Optimising the amount, type, source, and ratio of phosphate-to-protein during the early stages of CKD, despite normal serum phosphate levels, may affect the rate of disease progression (KDIGO 2017). A healthy balanced diet, containing natural sources of meat and plant-based foods, should be encouraged (Joshi et al. 2019; Adair and Bowden, 2020; Joshi et al. 2021; Rose and Strombom, 2019). Home-cooked meals are preferable, as processed foods contain a significant number of additives (in particular, inorganic phosphates and sodium) (Joshi et al. 2021; Kalantar-Zadeh et al. 2010). The nutritional prescription should consider energy, macronutrients, fluids, sodium, potassium, micronutrients, and calcium/phosphorus/ vitamin D (Nelms et al. 2021).

As children progress to CKD stages 4 and 5, the dietitian must respond to the changing and evolving dietary needs of the child. The fluctuating clinical and biochemical disturbances demand a regular review of biochemistry and fluid balance (Nelms et al. 2021). As serum phosphate and potassium levels start to rise, nutritional measures continue to play a significant role in the management and optimisation of cardiac and bone health. When serum phosphate levels are normal, in the context of serum PTH concentrations exceeding the target range, a moderate dietary phosphate restriction is encouraged to prevent and manage hyperparathyroidism, whilst optimising growth, nutrition, and bone mineralization (McAlister and Pugh et al. 2020). Optimal dietary management requires the constant appraisal and readjustment of each child's bespoke nutritional prescription by an experienced dietitian (Nelms et al. 2020), and the review of prescribed medication such as phosphate binders and anti-reflux agents to augment their effects (Ibrahim et al. 2013). The KDOQI (2005) and NKD (2009) guidelines recommend starting to monitor bone biochemistry at CKD Stage 2.

Infants and children may present with particular problems such as anorexia, vomiting, and body image changes, causing significant anxiety for parents (Tong et al. 2010). An understanding of the psychosocial effects of CKD often proves to be as important as dietary advice (Nicholas et al. 2011; Foster et al. 2012).

Ultimately, the dietary management of children with CKD is dependent on age, stage of CKD (Nelms et al. 2020), and an individual nutritional assessment, with particular attention paid to growth parameters. Oral nutritional supplements may have an important role and are frequently used (Rees et al. 2021; Rees and Jones 2013). However, experience has shown that attempting to achieve adequate nutrition orally can be stressful for families (Tong et al. 2010) due to issues relating to vomiting, palatability, and compliance.

A proactive approach to maintaining good nutrition and growth, without the use of growth hormone, has resulted in a programme of early instigation of dialysis or pre-emptive transplantation, in combination with nutritional support (Laakkonen et al. 2010). Early and intensive nutritional management is recommended in the KDOQI nutritional guidelines (2008) and Paediatric Renal Nutrition Taskforce clinical practice recommendations (Rees et al. 2020). Although NG tubes are used successfully, supplementary feeding using a gastrostomy button device may be more suitable in the long term (Foster et al. 2012; Rees and Jones 2013). However, there is some concern that gastrostomy feeding may predispose to obesity (Sienna et al. 2010), especially when children are relatively inactive. This is of particular concern in children receiving PD, due to the absorption of glucose from the dialysate. The gastrostomy button also provides a convenient route for the administration of medication and fluids, which has undoubted benefits for the child and family.

Dialysis is seen only as a holding measure prior to kidney transplantation. Most children do very well and resume normal eating and drinking post-transplant (Khweir et al. 2020). However, even if the transplant is

successful, with normal kidney function attained, concerns remain that there may be a prolonged transition to exclusive oral nutrition in infants and children who commenced nutritional support via an enteral route early in life. Support should be provided to encourage ongoing oral stimulation from the time of commencement of tube feeding (Khweir et al. 2020). Such children may continue to require a period of nutritional support post-transplant. Conversely, the lifting of dietary restrictions and initiation of steroid treatment in other children may require energy intake to be reduced to prevent rapid weight gain and obesity – a growing problem in children with CKD (Foster et al. 2010; Rodig et al. 2014). The use of steroid-sparing regimens alongside a healthy, no-added-salt diet and exercise should be encouraged with ongoing dietetic advice.

Maintaining good nutrition in this group of children requires the collaborative efforts of a multidisciplinary team (Foster et al. 2012). An agreed philosophy of nutritional care and dietetic time to attend ward rounds regularly, outpatient clinics, and psychosocial meetings, are essential. Home and school visits with frequent telephone contact are also invaluable support measures.

CONCLUSION

This chapter has provided the opportunity for the reader to improve current theoretical and practical knowledge of kidney nutrition. However, dietary advice is constantly changing as a result of new research findings and evidence-based guidelines. It is important that a positive effort is made to continuously review practice and to always involve patients and their families in decision-making.

REFERENCES

- Anderson J, Peterson K, Bourne D, Boundy E. (2018). Evidence Brief: Use of Intradialytic Parenteral Nutrition (IDPN) to Treat Malnutrition in Hemodialysis Patients [Internet]. Washington (DC): Department of Veterans Affairs (US)
- Armas, L.A.G. and Heaney, R.P. (2011). Vitamin D: the iceberg nutrient. *Journal of Renal Nutrition* 21: 134–139.
- Arora, S., Mattina, C., McAnenny, C. et al. (2012). Assessment of Nutritional Status in Patients with Cirrhosis: MUST is Not a Must. MSc thesis, University of Surrey.
- Baker, R., Jardine, A., and Andrews, P. (2017). Renal Association clinical practice guideline in post-operative care in the kidney transplant recipient. *BMC Nephrology* 18: 174.
- Benini, O., D'Alessandro, C., Gianfaldoni, D. et al. (2011). Extra-phosphate load from food additives in commonly eaten foods: a real and insidious danger for renal patients. *Journal of Renal Nutrition* 21: 303–308.
- Brenner, B. (1983). Hemodynamically mediated glomerular injury and the progressive nature of kidney disease. *Kidney International* 23: 647–655.
- Brown, T.J., Williams, H., Mafrici, B., Jackson, H.S., Johansson, L., Willingham, F., McIntosh, A. and MacLaughlin, H.L. (2021). Dietary interventions with dietitian involvement in adults with chronic kidney disease: A systematic review. *J Hum Nutr Diet*, 34: 747–757. <https://doi.org/10.1111/jhn.12870>
- Broyer, M., Le Bihan, C., Charbit, M. et al. (2004). Long-term social outcome of children after kidney transplantation. *Transplantation* 77: 1033–1037.
- Burton J et al. (2018). Commentary on the KDIGO Guideline on the Diagnosis, Evaluation, Prevention and Treatment of CKD-MBD. <https://ukkidney.org/sites/renal.org/files/FINAL-KDIGO-CKD-MBD-commentary-Final-for-publication.pdf> Accessed 2018 (accessed 13 Nov 2023).

- Byrne, F., Barbara Gillman, Mairead Kiely, Maria Bowles, Pauline Connolly, Joyce Earlie, Jean Murphy, Theresa Rennick, Emer O'Reilly, Frances Shiely, Patricia Kearney, Joseph Eustace (2021). Revising Dietary Phosphorus Advice in Chronic Kidney Disease G3-5D, *Journal of Renal Nutrition* 31 (2): 132–143.
- Caldeira, D., Amaral, T., David, C. et al. (2011). Educational strategies to reduce serum phosphorus in hyperphosphatemic patients with chronic kidney disease: a systematic review with meta-analysis. *Journal of Renal Nutrition* 21: 285–294.
- Campbell, K. (2013). Providing nutrition support in pre-dialysis chronic kidney disease. *Journal of Renal Nursing* 5 (3): 68–72.
- Canada–USA Peritoneal Dialysis Study Group (1996). Adequacy of dialysis and nutrition in continuous peritoneal dialysis: association with clinical outcomes. *Journal of the American Society of Nephrology* 7: 198–207.
- Carrero, J.J., Stenvinkel, P., and Cuppari, L. (2013). Etiology of the protein-energy wasting syndrome in chronic kidney disease: a consensus statement from the International Society of Renal Nutrition and Metabolism (ISRNM). *Journal of Renal Nutrition* 23 (2): 77–90.
- Chadban, S., Howell, M., Twigg, S. et al. (2010). Prevention and management of chronic kidney disease in type 2 diabetes. *Nephrology* 15: S162–S194.
- Chauveau, P., Aparicio, M., Bellizzi, V., et al. (2018). Mediterranean diet as the diet of choice for patients with chronic kidney disease, *Nephrology Dialysis Transplantation* 33 (5): 725–735.
- Cheung, A.K., Chang, T.I., Cushman, W.C., et al. (2021). Executive summary of the KDIGO 2021 Clinical Practice Guideline for the Management of Blood Pressure in Chronic Kidney Disease. *Kidney Int.* 99 (3): 559–569. doi: 10.1016/j.kint.2020.10.026.
- Churchill, D.N., Taylor, D.W., and Kesehaviiah, P.R. (1996). Adequacy of dialysis and nutrition in continuous peritoneal dialysis: association with clinical outcomes. *Journal of the American Society of Nephrology* 7: 198–207.
- Clapp, E.L. and Bevington, A. (2011). Exercise induced biochemical modifications in muscle in chronic kidney disease: occult acidosis as a potential factor limiting the anabolic effect of exercise. *Journal of Renal Nutrition* 21 (1): 57–60.
- Clase, C.M., Carrero, J.J., Ellison, D.H., et al. (2020). Potassium homeostasis and management of dyskalemia in kidney diseases: conclusions from a Kidney Disease: Improving Global Outcomes (KDIGO) Controversies Conference. *Kidney Int.* 97 (1): 42–61.
- Clegg, D.J., Headley, S.A., and Germain, M.J. (2020). Impact of Dietary Potassium Restrictions in CKD on Clinical Outcomes: Benefits of a Plant-Based Diet *Kidney Med.* 2 (4): 476–487.
- de Brito-Ashurst, I., Perry, L., Sanders, T.A. et al. (2011). Barriers and facilitators of dietary sodium restriction amongst Bangladeshi chronic kidney disease patients. *Journal of Human Nutrition and Dietetics* 24 (1): 86–95.
- de Mutsert, R., Grootendurst, D.C., Boeschoten, E.W. et al. (2009). SGA of nutritional status is strongly associated with mortality in chronic dialysis patients. *American Journal of Clinical Nutrition* 89: 787–793.
- Desloovere, A., Renken-Terhaardt, J., Tuokkola, J. et al. (2021). The dietary management of potassium in children with CKD stages 2–5 and on dialysis – clinical practice recommendations from the Pediatric Renal Nutrition Taskforce. *Pediatric Nephrology* 36: 1331–1346. <https://doi.org/10.1007/s00467-021-04923-1>
- Detsky, A.S., McLaughlin, J.R., Baker, J.P. et al. (1987). What is subjective global assessment of nutritional status? *Journal of Parenteral and Enteral Nutrition* 11: 8–13.
- Diabetes UK (2018). Evidence-Based Nutrition Guidelines for the Prevention and Management of Diabetes, <https://www.diabetes.org.uk/professionals/position-statements-reports/food-nutrition-lifestyle/evidence-based-nutrition-guidelines-for-the-prevention-and-management-of-diabetes> Accessed 13 Nov 2023
- Dukkipati, R., Kalantar-Zadeh, K., and Kopple, J.D. (2010). Is there a role for intradialytic parenteral nutrition? A review of the evidence. *American Journal of Kidney Disease* 55 (2): 352–364.
- EBPG (2002). European best practice guidelines for renal transplantation. *Nephrology Dialysis Transplantation* 17 (suppl. 4): 50–55.
- EBPG (2007). EBPG guideline on nutrition. *Nephrology Dialysis Transplantation* 22 (suppl. 2): ii45–ii87.
- Elsayed, E.F., Tighiouart, H., Weiner, D.E. et al. (2008). Waist to hip ratio and body mass index as risk factors for cardiovascular events in CKD. *American Journal of Kidney Disease* 52: A45–A46.
- Engel, B., Kon, S.P., and Raftery, M.J. (1995). Identification of malnutrition in haemodialysis patients. *Journal of Renal Nutrition* 5 (2): 62–66.
- ESPEN (2002). ESPEN guidelines for nutrition screening. *Clinical Nutrition* 22 (4): 415–421.
- Fine, R.N., Martz, K., and Stablein, D. (2010). What have 20 years of data from the North American Pediatric Renal Transplant Cooperative Study taught us about growth following renal transplantation in infants, children, and adolescents with end-stage renal disease? *Pediatric Nephrology* 25: 739–746.
- Fish et al. (2022). Commentary on NICE guideline NG136 <https://ukkidney.org/sites/renal.org/files/FINAL%20UKKA%20NICE-KDIGO%20commentary%20December%202022.pdf> (accessed 13 Nov 2023).
- Fischbach, M., Fothergill, H., Seuge, L. et al. (2011). Dialysis strategies to improve growth in children with chronic kidney disease. *Journal of Renal Nutrition* 21 (1): 43–46.
- Fisher, K., Paxton, R., Jackson, H. et al. (2010). Comparison of screening tools in patients undergoing haemodialysis. Paper presented at the BDA Research Conference, London, 2010.
- Fissell, R.B., Bragg-Gresham, J.L., Gillespie, B.W. et al. (2004). International variation in vitamin prescription and association with mortality in the Dialysis Outcomes and Practice Patterns Study (DOPPS). *American Journal of Kidney Disease* 44 (2): 293–299.
- Foster, B.J., McCauley, L., and Mak, R.H. (2012). Nutrition in infants and very young children with chronic kidney disease. *Pediatric Nephrology* 27: 1427–1439.

- Foster, B.J., Martz, K., Gowrishankar, M. et al. (2010). Weight and height changes and factors associated with greater weight and height gains after pediatric renal transplantation: a NAPRTCS study. *Transplantation* 89: 1103–1112.
- Fouque, D., and Laville, M. (2009). Low protein diets for chronic kidney disease in non-diabetic adults. *Cochrane Database of Systematic Reviews*.
- Fouque, D., Wang, P., Laville, M. et al. (2000). Low protein diets delay end-stage renal disease in non-diabetic adults with chronic renal failure. *Nephrology Dialysis Transplantation* 15: 1986–1992.
- Fouque, D., Kalantah-Zadeh, K., Kopple, J. et al. (2008). A proposed nomenclature and diagnostic criteria for protein energy wasting in acute and chronic kidney disease. *Kidney International* 73: 391–398.
- Friedman, A.N. (2006). Adiposity in dialysis: good or bad? *Seminars in Dialysis* 19 (2): 136–140.
- Friedman, A.N., and Fadem, S.Z. (2010). Reassessment of albumin as a nutritional marker in kidney disease. *Journal of the American Society of Nephrology* 21 (2): 223–230.
- Ginn, H., Rigalleau, V., and Aparicio, M. (1999). Which diet for diabetic patients with chronic renal failure? *Nephrology Dialysis Transplantation* 14: 2577–2579.
- Goldfarb, C. L., Galpern, J., Moore, L., et al. (2021). A narrative review of dietary approaches for kidney transplant patients. *Kidney Int Rep.* 7: 1764–1774. doi: 10.1016/j.ekir.2021.04.009.
- Gonzalez-Parra, E., Gracia-Iguacel, C., Egido, J. et al. (2012). Phosphorus and nutrition in kidney disease. *International Journal of Nephrology* <https://doi.org/10.1155/2012/597605>.
- Hanna, R. M., Ghobry, L., Wassef, O., et al. (2020). A practical approach to nutrition, protein-energy wasting, sarcopenia, and cachexia in patients with chronic kidney disease. *Blood Purif* 49: 202–211.
- Hahn, D., Hodson, E.M., Fouque, D. (2020). Low protein diets for non-diabetic adults with chronic kidney disease. *Cochrane Database of Systematic Reviews* 10: CD001892. doi: 10.1002/14651858.CD001892.pub5.
- Hadfield, C. (1992). The nutritional adequacy of a low protein diet. *Journal of Renal Nutrition* 2 (3), (suppl. 1): 37–41.
- Harambat, J., Bonthuis, M., van Stralen, K.J. et al. (2014). Adult height in patients with advanced CKD requiring renal replacement therapy during childhood. *Clinical Journal of the American Society of Nephrology* 9: 92–99.
- Heiwe, S., and Jacobson, S.H. (2011). Exercise training for adults with chronic kidney disease. *Cochrane Database of Systematic Reviews* (Issue 10): CD003236. <https://doi.org/10.1002/14651858.CD003236.pub2>.
- Holt, S. and Goldsmith, D. (2010). Cardiovascular Disease in CKD. <http://www.renal.org/Clinical/GuidelinesSection/CardiovascularDiseaseInCKD.aspx> (accessed 20 May 2013).
- Hunt, L. (2011). Provision of water-soluble vitamin supplementation for haemodialysis patients. *Journal of Human Nutrition and Dietetics* 24 (3): 289–290.
- Ibrahim, N., Wong, I.C.K., Patey, S. et al. (2013). Drug-related problem in children with chronic kidney disease. *Pediatric Nephrology* 28: 25–31.
- Ikizler, T.A. (2011). Exercise as an anabolic intervention in patients with end stage renal disease. *Journal of Renal Nutrition* 21 (1): 52–56.
- Ikizler, T.A. (2013). A patient with CKD and poor nutritional status. *Clinical Journal of the American Society of Nephrology* 8: 2174–2182.
- Ikizler, T.A. and Hakim, R.M. (1996). Nutrition in end-stage renal disease. *Kidney International* 50: 343–357.
- Ikizler, T.A., Cano, N.J., Franch, H. et al. (2013). Prevention and treatment of protein energy wasting in chronic kidney disease patients: a consensus statement by the International Society of Renal Nutrition and Metabolism. *Kidney International* 84: 1096–1107.
- Ikizler, T.A., Burrowes, J.D., Byham-Gray, L.D., et al. (2020). KDOQI Nutrition in CKD Guideline Work Group. KDOQI clinical practice guideline for nutrition in CKD: 2020 update. *Am J Kidney Dis.* 76 (3) (suppl 1): S1–S107.
- Jackson HS, MacLaughlin HL, Vidal-Diez A, Banerjee D. (2019). A new renal inpatient nutrition screening tool (Renal iNUT): a multicenter validation study. *Clin Nutr.* 38 (5): 2297–2303. doi: 10.1016/j.clnu.2018.10.002.
- Jankowska, M., Rutkowski, B., and Debska-Slizień, A. (2017). Vitamins and microelement bioavailability in different stages of chronic kidney disease. *Nutrients* 9 (3): 282.
- Johnson, D.W. (2006). Dietary protein restriction as a treatment for slowing chronic kidney disease progression: the case against. *Nephrology* 11: 58–62.
- Kalantar-Zadeh, K., Kopple, J.D., Block, G. et al. (2001). A malnutrition-inflammation score is correlated with morbidity and mortality in maintenance hemodialysis patients. *American Journal of Kidney Disorders* 38 (6): 1251–1263.
- Kalantar-Zadeh, K., Gutekunst, L., Mehrotra, R. et al. (2010). Understanding sources of dietary phosphorus in the treatment of patients with chronic kidney disease. *Clinical Journal of the American Society of Nephrology* 5 (3): 519–530.
- Kidney Disease: Improving Global Outcomes (KDIGO) (2012). Clinical practice guidelines for the management of blood pressure in chronic kidney disease. *Kidney International Supplements* 2 (5).
- Kidney Disease: Improving Global Outcomes (KDIGO) Glomerular Diseases Work Group (2021). Clinical practice guideline for the management of glomerular diseases. *Kidney Int.* 100 (4S): S1–S276. doi: 10.1016/j.kint.2021.05.021.
- KDIGO (2017). Clinical practice guideline update for the diagnosis, evaluation, prevention, and treatment of chronic kidney disease—mineral and bone disorder (CKD-MBD). *Kidney International Supplements* 7: 1–59.
- K/DOQI (2000). National Kidney Foundation. Clinical practice guidelines for nutrition in chronic renal failure. *American Journal of Kidney Diseases* 35 (suppl. 2): S1–S140.

- K/DOQI (2003a). National Kidney Foundation. K/DOQI clinical practice guidelines for managing dyslipidemias in chronic kidney disease. *American Journal of Kidney Diseases* 41 (suppl. 3): S1–S92. http://www.kidney.org/professionals/kdoqi/guidelines_lipids/index.htm (accessed 20 May 2013).
- K/DOQI (2003b). Clinical Practice Guidelines for Bone Metabolism and Disease in Chronic Kidney Disease. http://www2.kidney.org/professionals/kdoqi/guidelines_bone/Guide4.htm.
- K/DOQI (2008). Clinical practice guidelines for nutrition in children with CKD: 2008 update. Executive summary. *American Journal of Kidney Diseases* 53: S11–S104.
- K/DOQI (2005). NKF KDOQI Guidelines. KDOQI Clinical Practice Guidelines for Bone Metabolism and Disease in Children with Chronic Kidney Disease. National Kidney Foundation.
- Klahr, S., Levey, A.S., Beck, G.J. et al. (1994). The effects of dietary protein restriction and blood-pressure control on the progression of chronic renal disease. *New England Journal of Medicine* 330: 878–884.
- Kopple, J.D., Storer, T., and Casburi, R. (2005). Impaired exercise capacity and exercise training in maintenance haemodialysis patients. *Journal of Renal Nutrition* 15 (1): 44–48.
- Kopple, J.D., Wolfson, M., Chertow, G.M. et al. (2000). Clinical practice guidelines for nutrition in chronic renal failure. *American Journal of Kidney Diseases* 35: S17–S140.
- Koufaki, P., Greenwood, S., Painter, P. et al. (2015). The BASES expert statement on exercise therapy for people with chronic kidney disease. *Journal of Sports Sciences* 33 (18): 1902–1907.
- Kuningas K, Driscoll J, Mair R, Day E, Sharif A. (2023) Short-term Healthy Lifestyle Intervention and Long-term Behavior Change After Kidney Transplantation: Findings from the CAVIAR Study. *Am J Kidney Dis.* 81 (2): 249–252. doi: 10.1053/j.ajkd.2022.08.020.
- Laakkonen, H., Happonen, J.-M., Marttinen, E. et al. (2010). Normal growth and intravascular volume status with good metabolic control during peritoneal dialysis in infancy. *Pediatric Nephrology* 25: 1529–1538.
- Lindley, E., Devine, Y., Hall, L. et al. (2005). A ward based procedure for assessment of fluid status in peritoneal dialysis patients using bioimpedance spectroscopy. *Peritoneal Dialysis International* 25 (suppl. 3): S46–S48.
- Liu, Z., Su, G., Guo, X. et al. (2015). Dietary interventions for mineral and bone disorder in people with chronic kidney disease. *Cochrane Database of Systematic Reviews* (Issue 9): CD010350. <https://doi.org/10.1002/14651858.CD010350.pub2>.
- Liu, P.J., Ma, F., Wang, Q.Y., He, S.L. (2018). The effects of oral nutritional supplements in patients with maintenance dialysis therapy: A systematic review and meta-analysis of randomized clinical trials. *PLoS One* 13 (9): e0203706. doi: 10.1371/journal.pone.0203706.
- Lin, P.C., Chou, C.L., Ou, S.H., et al. (2021). Systematic review of nutrition supplements in chronic kidney diseases: A GRADE approach. *Nutrients* 13 (2): 469. doi: 10.3390/nu13020469.
- Loser, C., Aschl, G., Hebutterne, X. et al. (2005). ESPEN guidelines on enteral nutrition – percutaneous endoscopic gastrostomy (PEG). *Clinical Nutrition* 24: 848–861.
- Lynch, K.E., Lynch, R., Curhan, G.C., et al. (2011). Prescribed dietary phosphate restriction and survival among hemodialysis patients. *Clinical Journal of the American Society of Nephrology* 6: 620–629.
- MacGregor, M.S. and Taal, M.W. (2011). Detection, monitoring and care of patients with CKD, <http://www.renal.org/Clinical/GuidelinesSection/Detection-Monitoring-and-Care-of-Patients-with-CKD.aspxarchived>.
- Makoff, R. (1999). Vitamin replacement therapy in renal failure patients. *Mineral Electrolyte Metabolism* 25: 349–351.
- Marsen, T.A., Beer, J., and Mann, H. (2017). Intradialytic parenteral nutrition in maintenance hemodialysis patients suffering from protein-energy wasting. Results of a multicenter, open, prospective, randomized trial. *Clinical Nutrition* 36: 107–117.
- McAlister, L., Pugh, P., Greenbaum, L. et al. (2020). The dietary management of calcium and phosphate in children with CKD stages 2–5 and on dialysis – clinical practice recommendation from the Pediatric Renal Nutrition Taskforce. *Pediatric Nephrology* 35: 501–518. <https://doi.org/10.1007/s00467-019-04370-z>.
- McCann, L. (1996). Subjective global assessment as it pertains to the nutritional status of dialysis patients. *Dialysis Transplant* 25: 190–202, 225.
- McMahon, E.J., Campbell, K.L., Bauer, J.D. et al. (2015). Altered dietary salt intake for people with chronic kidney disease. *Cochrane Database of Systematic Reviews* 2015 (2): CD010070.
- Melamed, M.L., Raphael, K.L. (2021). Metabolic acidosis in CKD: A review of recent findings. *Melamed*. 3 (2): 267–277. doi: 10.1016/j.xkme.2020.12.006.
- Mekahli, D., Shaw, V., Ledermann, S.E. et al. (2010). Long-term outcome of infants with severe chronic kidney disease. *Clinical Journal of the American Society of Nephrology* 5 (1): 10–17.
- Memmer, D. (2013). Implementation and practical application of the nutrition care process in the dialysis unit. *Journal of Renal Nutrition* 23 (1): 65–73.
- Mikhail, A., Brown, C., Williams, J.A., et al. (2017). Renal Association clinical practice guideline on anaemia of chronic kidney disease. *BMC Nephrol.* 18 (1): 345. doi: 10.1186/s12882-017-0688-1.
- Mikhail, A., Brown, A., Williams, J.I., et al. (2010). Renal association clinical practice guideline on anaemia of CKD. *BMC Nephrology* 2017 (18): 345.
- Mikhail, A., Brown, C., Williams, A., et al. (2017). Clinical Practice Guideline Anaemia of Chronic Kidney Disease. <https://renal.org/wp-content/uploads/2017/06/anaemia-of-chronic-kidney-disease-5d84a231181561659443ff000014d4d8.pdf>
- Moe, S.M., Zidehsarai, M.P., Chambers, M.A., et al. (2011). Vegetarian compared with meat dietary protein source and phosphorus homeostasis in chronic kidney disease. *Clin J Am Soc Nephrol.* 6 (2): 257–264. doi: 10.2215/CJN.05040610.

- National Institute for Health and Clinical Excellence (2006a). *Nutritional Support in Adults – Oral Supplements, Enteral Tube Feeding and Parenteral Nutrition*. London: NICE.
- National Institute for Health and Clinical Excellence (2006b). CG43; 2006 Obesity: NICE Guideline, www.nice.org.uk/guidance/CG43/NICEGuidance (accessed 20 May 2013).
- National Institute for Health and Care Excellence (2013). CG157 Chronic kidney disease (stage 4 or 5): management of hyperphosphataemia. www.nice.org.uk/guidance/cg157
- National Institute for Health and Care Excellence (2015). Chronic kidney disease: managing anaemia. <https://www.nice.org.uk/guidance/ng8>
- National Institute for Health and Care Excellence (2021). Chronic kidney disease: assessment and management. <https://www.nice.org.uk/guidance/ng203>
- National Institutes of Health (1993). Morbidity and mortality of dialysis. NIH Consensus Statement, National Library of Medicine, Office of Medical Applications of Research, National Institutes of Health, Bethesda, MD, pp. 1–33.
- Naylor, H.L., Jackson, H., Walker, G.H., et al. (2013). British Dietetic Association evidence-based guidelines for the protein requirements of adults undergoing maintenance haemodialysis or peritoneal dialysis on behalf of the Renal Nutrition Group of the British Dietetic Association. *Journal of Human Nutrition and Dietetics* 26: 315–328.
- Nicholas, D.B., Picone, G., and Selkirk, E.K. (2011). The lived experiences of children and adolescents with end-stage renal disease. *Qualitative Health Research* 21: 162–173.
- Nolte Fong, J.V., and Moore, L.M. (2018). Nutrition trends in kidney transplant recipients: the importance of dietary monitoring and need for evidence-based recommendations *Frontiers Medicine* 5 <https://www.frontiersin.org/articles/10.3389/fmed.2018.00302/full> (accessed 13 Nov 2023).
- Obi Y, Qader H, Kovesdy CP, Kalantar-Zadeh K. (2015). Latest consensus and update on protein-energy wasting in chronic kidney disease. *Curr Opin Clin Nutr Metab Care* 18 (3): 254–262.
- Palmer, S.C., Maggo, J.K., Campbell, K.L. et al. (2017). Dietary interventions for adults with chronic kidney disease. *Cochrane Database of Systematic Reviews* (Issue 4): CD011998. <https://doi.org/10.1002/14651858.CD011998.pub2>.
- Pederson, P.U. (2005). Nutritional care: the effectiveness of actively involving older patients. *Journal of Clinical Nursing* 14: 247–255.
- Pedrin, M.T., Levey, A.S., Lau, J. et al. (1996). The effect of protein restriction on the progression of diabetic and nondiabetic renal disease: a meta-analysis. *Annals of Internal Medicine* 124: 629–632.
- Renal Nutrition Group (2015). Consensus statement on nutrition support and the use of oral nutritional supplements in patients with stages 4–5 chronic kidney disease. https://static-nocdn.abbottnutrition.com/cms/preview/abbottnutrition-2016.com/img/consensus_guide_approved_august_2015_accessible.pdf (accessed 13 Nov 2023).
- Royal College of Paediatrics and Child Health (2011). *Improving the Standard of Care of Children with Kidney Disease Through Paediatric Nephrology Networks*. London: RCPCH.
- Rees, L. and Jones, H. (2013). Nutritional management and growth in children with chronic kidney disease. *Pediatric Nephrology* 28: 527–536.
- Robertson, L.M., Waugh, N., and Robertson, A. (2007). Protein restriction for diabetic renal disease. *Cochrane Database of Systematic Reviews* 4: CD002181.
- Rocha, S., Fonseca, I., Silva, N. et al. (2011). Impact of pediatric kidney transplantation on long-term professional and social outcomes. *Transplantation Proceedings* 43: 120–124.
- Rocco, M.V. and Makoff, R. (1997). Appropriate vitamin therapy for dialysis patients. *Seminars in Dialysis* 10: 272–277.
- Rodig, N.M., McDermott, K.C., Schneider, M.F. et al. (2014). Growth in children with chronic kidney disease: a report from the kidney disease in children study. *Pediatric Nephrology* 29: 1987–1995.
- Royal College of Physicians (2002). *Glucocorticoid Induced Osteoporosis; A Concise Guide to Prevention and Treatment*, <http://bookshop.rcplondon.ac.uk/contents/pub89-64206b70-b147-4976-9ee1-bf4948458468.pdf> (accessed 20 May 2013).
- SACN-COT (2017) Statements on potassium-based sodium replacers https://assets.publishing.service.gov.uk/media/5a82b61bed915d74e34032cc/SACN_COT_-_Potassium-based_sodium_replacers.pdf (accessed 13 Nov 2023).
- Sayce, H.A., Rowe, P.A. and McGonigle, R.J.S. (2000). Percutaneous endoscopic gastrostomy feeding in haemodialysis out-patients. *Journal of Human Nutrition and Dietetics* 13: 333–341.
- Seikaly, M.G., Salhab, N., Warady, B.A. et al. (2007). Use of rhGH in children with chronic kidney disease: lessons from NAPRTCS. *Pediatric Nephrology* 22: 1195–1204.
- Sexton, J. and Vincent, M. (2004). Remedying calcium and phosphate problems in chronic kidney disease. *The Pharmaceutical Journal* 274: 561–564.
- Sienna, J.L., Saqan, R., Teh, J.C. et al. (2010). Body size in children with chronic kidney disease after gastrostomy tube feeding. *Pediatric Nephrology* 25: 2115–2121.
- Sigrist, M.K., Levin, A., and Tejan, A.M. (2010). Systematic review of evidence for the use of intradialytic parenteral nutrition in malnourished haemodialysis patients. *Journal of Renal Nutrition* 20 (1): 1–17.
- Steddon, S. and Sharples, E. (2015). Renal Association Guidelines CKD Mineral and Bone Disorders, <https://renal.org/wp-content/uploads/2017/06/ckd-mineral-and-bone-disorders-ckd-mbd204ca231181561659443ff000014d4d8.pdf> (accessed 20 Dec 2017).
- Steiber, A.L. and Kopple, J.D. (2011). Vitamin status and needs for people with stages 3–5 chronic kidney disease. *Journal of Renal Nutrition* 21 (5): 355–368.
- Stenvinkel, P. (2003). Interactions between inflammation, oxidative stress, and endothelial dysfunction in end-stage renal disease. *Journal of Renal Nutrition* 13: 144–148.

- Stratton, R.J., Bircher, G., Fouque, D. et al. (2005). Multinutrient oral supplements and tube feeding in maintenance dialysis: a systematic review and meta-analysis. *American Journal of Kidney Diseases* 46 (3): 387–405.
- Stratton, R.J., Green, C.J., and Elia, M. (2003). *Disease Related Malnutrition: An Evidence Based Approach*. Wallingford: CABI International.
- Su, G., Saglimbene, V., Wong, G., et al. (2022). Dietary phosphorus, its sources, and mortality in adults on haemodialysis: The DIET-HD Study. *Nutrients* 14 (19): 4064. doi: 10.3390/nu14194064.
- Suetta, C., Magnusson, S.P., Rosted, A. et al. (2004). Resistance training in the early postoperative phase reduces hospitalization and leads to muscle hypertrophy in elderly hip surgery patients – a controlled, randomized study. *Journal of the American Geriatrics Society* 52: 2016–2022.
- Sutton, D., Ovington, S., and Engel, B. (2014). A multi-centre, randomised trial to assess whether increased dietary fibre intake (using a fibre supplement or high-fibre foods) produces healthy bowel performance and reduces laxative requirement in free living patients on peritoneal dialysis. *Journal of Renal Care* 40 (3): 157–163.
- Taylor, G.S., Patel, V., Spencer, S. et al. (2002). Long-term use of 1.1% amino acid dialysis solution in hypoalbuminemic continuous ambulatory peritoneal dialysis patients. *Clinical Nephrology* 58: 445–450.
- Tjiong, H.L., van den Berg, J.W., Wattimena, J.L. et al. (2005). Dialysate as food: combined amino acid and glucose dialysate improves protein anabolism in renal failure patients on automated peritoneal dialysis. *Journal of the American Society of Nephrology* 16: 1486–1493.
- Todorovic, V.E. and Mafrici, B. (2018). *A Pocket Guide to Clinical Nutrition*. Nottingham: British Dietetic Association.
- Tonelli, M., Webbe, N., Hemmelgarn, B. et al. (2009). Trace Elements in Haemodialysis Patients: A Systematic Review and Meta-Analysis. <http://biomedcentral.com/1741-7015/7/25> (accessed 20 May 2013).
- Tong, A., Lowe, A., Sainsbury, P., and Crain, J.C. (2010). Parental perspectives on caring for a child with chronic kidney disease: an in-depth interview study. *Child: Care, Health and Development* 36: 549–557.
- UK Prospective Diabetes Study (UKPDS) (1998). Intensive blood-glucose control with sulphonylureas or insulin compared with conventional treatment and risk of complications in patients with type 2 diabetes (UKPDS 33). *Lancet* 352: 837–853.
- Vennegoor, M. (ed.) (1992). *Enjoying Food on a Renal Diet*. London: King Edward's Fund for London.
- Visser, M., Deeg, D.J., and Lips, P. (2003). Low vitamin D and high parathyroid hormone levels as determinants of loss of muscle strength and muscle mass (sarcopenia): the Longitudinal Aging Study, Amsterdam. *Journal of Clinical Endocrinology and Metabolism* 88 (12): 5766–5772.
- Visser, R., Dekker, F.W., Boeschoten, E.W. et al. (1999). Reliability of the 7-point subjective global assessment scale in assessing nutritional status of dialysis patients. *Advances in Peritoneal Dialysis* 15: 222–225.
- Vitaflow (2023). Paediatric Renal Nutrition Taskforce: Managing phosphate intake: a guide for young people. <https://www.vitaflow.com/sites/default/files/2023-03/managing-phosphate-guide-for-young-people-march-2023.pdf>.
- Vitaflow (2021). Paediatric Renal Nutrition Taskforce: Following a low potassium diet: a guide for families. https://www.vitaflow.com/sites/default/files/2022-07/following-a-low-potassium-diet_a-guide-for-families_children.pdf.
- Von Schnakenburg, C., Feneburg, R., Plank, C. et al. (2006). Percutaneous endoscopic gastrostomy in children on PD. *Peritoneal Dialysis International* 26 (1): 69–77.
- Wesseling-Perry, K., Pereira, R.C., Tseng, C.-H. et al. (2012). Early skeletal and biochemical alterations in pediatric chronic kidney disease. *Clinical Journal of the American Society of Nephrology* 7: 146–152.
- WHO (1998). *Physical Status: The Use and Interpretation of Anthropometry. Report of a WHO Expert Committee*, WHO Technical Report Series 854. Geneva: World Health Organization.
- Wolk, R. (1993). Micronutrition in dialysis. *Nutrition in Clinical Practice* 8: 267–276.
- Woodrow, G., Fan, S.L., Reid, C., et al. (2017). Renal Association guidelines on peritoneal dialysis in adults and children. *BMC Nephrology* 18: 333.
- Wright, M. and Jones, C. (2011). Renal Association clinical practice guideline on nutrition in CKD. *Nephron Clin Pract* 118 (suppl 1): c153–c164 <https://doi.org/10.1159/000328067>.
- Wright, M., Southcott, E., and Stuart, W. (2019). The Renal Association. Clinical practice guideline. Undernutrition in chronic kidney disease. *Почку*, 8 (2): 129–131.
- Yale, J.F. (2005). Oral antihyperglycaemic agents and renal disease: new agents, new concepts. *Journal of the American Society of Nephrology* 16 (suppl. 1): S7–S10.
- Yokum, D., Glass, G., Cheung, C.F., et al. (2008). Evaluation of a phosphate management protocol to achieve optimum serum phosphate levels in hemodialysis patients. *Journal of Renal Nutrition* 18 (6): 521–529.

12.A: CALCULATION OF BODY MASS INDEX AND IDEAL BODY WEIGHT

Body mass index (BMI) can be calculated by dividing the weight in kg by the height in metres squared. If the patient has oedema, the BMI will be overestimated and is not valid. In estimating oedema-free body weight (BW_{ef}), weight should be measured after haemodialysis (HD) or after drainage of dialysis fluid in peritoneal dialysis (PD).

A person weighs 65 kg and is 1.70 m tall.

$$BMI = 65 / (1.7 \times 1.7) = 22.5 \text{ kg m}^{-2}$$

Normal range: 18.5–24.9.

Underweight <18.5.

Pre-obese (overweight): 25–29.9.

Obese class I : 30–34.9.

Obese class II: 35–39.9 (obese).

Obese class III: >40 (morbidly obese).

The K/DOQI guidelines recommend the use of adjusted oedema-free body weight (aBW_{ef}) to calculate protein or energy requirements or to assess intake. The following method can be used. Standard body weight: a BMI between 18.5 and 24.9 kg m^{-2} and its corresponding weight in kilogrammes, is considered within the normal range (WHO 1998). However, given the increased mortality of patients at the lower end of the ‘normal’ range, it may be prudent to calculate the standard weight for a BMI of 23 kg m^{-2} and this can be used in the following equation. The following equation has been suggested:

$$IBW = aBW_{ef} = BW_{ef} + \left(\left(\text{standard body weight} - BW_{ef} \right) \times 0.25 \right)$$

These figures should be used to calculate protein and energy requirements for individual patients.

The important point for audit purposes and comparison across kidney units is to note clearly how you have calculated ideal body weight (IBW). As there is no consensus regarding this issue a simpler method would be to use the weight corresponding to a BMI of 23 kg m^{-2} .

12.B: SEVEN-POINT SUBJECTIVE GLOBAL ASSESSMENT

Name Hospital No D.o.B

Date					
Overall weight change over last 6 months					
❖ Gain (7)/<5% loss (6)					
❖ 5–10% sustained loss (4–5)					
❖ >10% sustained loss (1)					
❖ >10% loss but gaining (relative to dry weight) (2–3)					
❖ >5–10% loss but gaining (4)					
Weight change over past 2 weeks					
❖ No change/normal weight (6–7)					
❖ Increased/increasing (rate 1 score above previous) (3–4–5)					
❖ Stable but below normal (relative to dry weight) (2–3)					
❖ Decreased/decreasing (1)					
Change in dietary intake compared to normal					
❖ Good intake/no change/small change (7)					
❖ Borderline intake/decreasing (3)					
❖ Poor intake/no change (2)					
❖ Poor intake/increasing (3–4–5)					
❖ Poor intake/decreasing (1)					
Duration/type of change in diet					
❖ <2 weeks, normal diet (7)					
❖ >2 weeks, sub-optimal normal diet (3)					
❖ Full fluid diet/NG (3–4–5)					
❖ Hypocaloric liquids (2)					
❖ Starvation (1)					
GI symptoms					
Nausea, Vomiting, Diarrhoea, Anorexia					
❖ None/few intermittent symptoms (7)					
❖ Some symptoms >2 weeks (3–4–5)					
❖ Most/all symptoms >2 weeks (1)					
Subcutaneous fat (triceps/chest)					
❖ Little or no depletion (6–7)					
❖ Moderate depletion some/all areas (3–4–5)					
❖ Severe depletion most/all areas (1–2)					
Muscle wasting (quads/deltoids)					
❖ Little or no depletion (6–7)					
❖ Moderate depletion some/all areas (3–4–5)					
❖ Severe depletion most/all areas (1–2)					
Total score:					

12.C: FOODS WITH A HIGH AND LOW SODIUM (SALT) CONTENT

It may not be possible to eliminate all the listed foods or meals, unless a low-sodium alternative is available. A compromise may be reached by allowing some salty foods for sandwiches or main meals but preparing the rest of the meals at home without salt. Adding herbs and spices during meal preparation or thereafter compensates for the loss of salt.

Foods with a high sodium content	Suitable alternative (always check with dietitian)
Dairy products	
Salted butter or margarine	Use unsalted or salt-reduced alternatives instead
Cheese, cheese spreads	
Meat and meat products	
Canned and cured meat products such as bacon, gammon, salt beef, corned beef, ham, tongue, all types of sausages, pâtés	Fresh-cooked meat
	Fresh-cooked poultry
	Fresh-cooked fish
Meat pies, quiches, and sausage rolls	Home-cooked meat
Processed meals	
Fast food-type meals	
Vegetables	
Canned vegetables, sauerkraut, instant potato powder, salted potato crisps	Fresh or frozen vegetables
Nuts	
Roasted and salted nuts	
Miscellaneous	
Salt, sea salt, salt substitutes such as Lo Salt, Solo, Selora	Herbs, spices
Mayonnaise, salad dressings	Homemade dressings, i.e. French dressing
Bottled sauces, pickles	Vinegar, lemon, lime juice
Canned or packet soups or ready-made soups	Homemade soup
Pasta sauce, curry paste, soya sauce	Homemade sauces
Meat or yeast extracts and bouillon cubes, packet gravy, gravy cubes, or powders	Use herbs and spices for curries
	Use fresh ingredients for pasta dishes
Foods containing monosodium glutamate	
Salted savoury snacks	
Asian foods	
Poppadums, samosas, other savoury snacks, chutneys, pickles, chevra, chana	
Greek foods	
Taramasalata, canned vine leaves, hummus	Homemade hummus
Chinese foods	
Dried fish, salted fish	
Peking duck and similar products	

12.D: FOODS WITH HIGH AND LOW PHOSPHORUS CONTENT

All foods with a high protein content also contain a fair amount of phosphorus. However, some of these foods are an essential part of the diet and cannot be eliminated.

The Paediatric Renal Nutrition Taskforce has done a lot of work to develop clinical practice recommendations, which considers the many factors impacting on phosphate and potassium bioavailability. The phosphorus table has been adapted to incorporate the Taskforce recommendations. (McAlister et al. 2020; Desloovere et al. 2021; Vitaflow 2023).

Foods with a high phosphorus content	Suitable alternative (always check with dietitian)
Cereals	
Natural Bran, All-Bran, Bran Flakes, Bran Buds, (can allow a small portion) cereals containing nuts	All other breakfast cereals (not chocolate based)
	Porridge
Rye bread (can allow a small portion)	Wholemeal or white bread, croissant
Crispbread containing rye (can allow)	Puri, pitta bread, chapatti, naan
Oatcakes (can allow a small portion), scones (avoid if containing Ph-based raising agent)	Yorkshire pudding (avoid if containing Ph-based raising agent)
Soya flour (can allow)	Flour, barley, sago
	Semolina, tapioca, cornflour, custard powder
	Pasta, noodles, rice, wild rice
Dairy products	
Milk, yoghurt (see allowance allocated by kidney dietitian)	Cream, soured cream, crème fraîche
Evaporated and condensed milk	Fromage frais, quark
Milk powder, Horlicks	Cottage cheese and curd cheese
Most types of hard cheese, e.g. cheddar (allow a reduced amount)	Full-fat or reduced-fat cream cheese, such as Boursin, Philadelphia, roulé, marscapone, ricotta, Vegan coconut, or soya oil cheese
Stilton (allow a reduced amount), processed cheese slices/strips/spreadable cheese	
Eggs (no more than one daily); however, these quantities may need to be adapted for vegetarian diets	Egg white, meringue
Meat and meat products	
Liver, kidney, liver pâté and liver sausage, black pudding, sausages	Beef, veal, lamb, pork, chicken, turkey, , meat pies (only if homemade) (see meal plan suggested by the kidney dietitian)
Fish and fish products	
Processed fish products (e.g. fish cakes/fingers, battered or crumbed fish)	Fresh or smoked fish, such as cod, haddock, halibut, plaice, mackerel, tuna
Fish paste	Tinned fish: mackerel, tuna, salmon, sardines, kippers, pilchards (only if without bones and skin)
	Cockles, mussels, squid
	Occasionally use: crab, lobster, prawns, scampi, trout
Vegetables	
Pulses, such as dried peas, dried beans, lentils, baked beans, chickpeas (all in moderation/good source of fibre)	All other vegetables

(Continued)

(Continued)

Foods with a high phosphorus content	Suitable alternative (always check with dietitian)
Plant-based protein Some processed plant-based meals/products, e.g. meat-free country pie, meat-free hot dogs, chicken-free crispy grills	Tofu, Quorn®, textured soya protein, soya or pea-based veggie burger, beans and pulses (e.g. lentils, kidney beans, and chickpeas)
Savoury snacks All types of nuts such as peanuts, peanut butter (may need to reduce intake of these naturally high in phosphate foods) Bombay mix, chevra, chana, ganthia Poppadoms	Popcorn, corn snacks
Sweets Chocolate, cocoa powder, Ovaltine, Mars bars, Snickers, Bounty, halva, burfi with nuts	Sweets, barley sugars, butterscotch, mint, fruit pastilles, starburst, sherbets, jelly babies, wine gums, marshmallows, Turkish delight, chewing gum, plain toffee and fudge, lollipops, ice lollies
Cakes and pastries Chocolate cake, Battenburg cake Any cakes and pastries containing chocolate or nuts Baked goods or puddings with phosphate-containing raising agents e.g. crumpets, muffins, scones, pastries, naan bread, and tortillas/wraps	All other types of cakes, biscuits, pastries (avoid Ph-based raising agents) Doughnuts, cream cakes, gingerbread
Biscuits Chocolate biscuits, Jaffa cakes All biscuits containing nuts or chocolate	Plain biscuits, such as Digestives Cream crackers, Rich Tea, shortbread, sponge fingers, cream-filled biscuits
Puddings Milk pudding, custard, bread pudding, Christmas pudding, sponge Chocolate mousse, chocolate ice cream, desserts containing nuts and chocolate	Pancakes, pastries, sweet or savoury, fruit jelly, sorbets, plain ice cream, cheesecake Avoid products containing Ph-based raising agents
Beverages Milk and milk drinks, such as milkshakes, Build-up, Complan, Nutrament, drinking chocolate, cocoa, Bourneville, Ovaltine, Jamaican punch, N.B. some soft drinks (dark coloured) contain added phosphate	Tea, coffee Soft drinks (usually light coloured), fruit squash, lemon barley, blackcurrant drink, lime juice cordial, Crusha syrup, rosehip syrup
Condiments and miscellaneous Meat and yeast extracts, such as Marmite, Bovril, Vegemite Marzipan, peanut butter (may allow a small portion), seeds such as sesame, tahini, chocolate, and nut spread (may allow a small portion)	Sugar, jam, marmalade, honey, lemon curd, golden syrup Gelatine, yeast, pickles, chutney, tomato ketchup, tomato purée, lemon juice, vinegar, mustard, mayonnaise, salad cream, salad dressing, tartar sauce, chilli sauce, soya sauce, herbs, and spices, apple sauce, cranberry sauce, redcurrant jelly, horseradish, mint sauce, mint jelly N.B (many of these may be high in salt)

12.E: FOODS WITH HIGH, AND LOWER POTASSIUM CONTENT

The potassium table has been adapted to incorporate the Paediatric Renal Nutrition Taskforce recommendations (Vitaflow 2021).

Foods with a high potassium content	Foods with a lower potassium content
Savoury snacks Bombay mix, curu snacks, all nuts including peanuts all types of seeds (allow a reduced amount of nuts and seeds), potato crisps, potato hoops, twiglets, vegetable samosas	Popcorn, corn snacks such as tortilla chips, rice cakes, and rice-based snacks, wheat-based snacks
Sweets and sweet snacks - Chocolate; plain, milk, white, and all sweets containing chocolate - Liquorice allsorts, toffees, fudge, and other sweets containing nuts, chocolate - Dried fruit; dried apples, dried apricots, dried banana chips, currants, dates, dried figs, prunes, raisins, sultanas, other dried fruit - Marzipan, treacle	- Sugar, jam, marmalade, honey, lemon curd, golden syrup - Boiled sweets, barley sugar, peppermint, Turkish delight, jelly babies, fruit pastilles, fruit gums, sherbets, marshmallows, lollipops, ice lollies, chewing gum - Crystallised, glaze fruit
Beverages - Coffee in excess - Milk powder and drinks containing milk powder, such as Ovaltine, Horlicks, Complan, Build-up, drinking chocolate, milk shakes, Nutrament, cocoa powder - Milk shakes - All fruit juices unless exchanged for fruit, cane sugar juice, vegetable juices; tomato juice, carrot juice	- Tea (milk from allowance) - Soft drinks; with low real fruit juice content, tonic, soda water, ginger beer, lemonade, fizzy water, bitter lemon - Fruit squash - Rice, oat milk - Water
Alcohol Ale, barley wine, beer, cider, lager, red wine, white wine, sherry, port	Spirits
Cereals and cereal products - All bran, bran flakes, oatbran flakes, cereals with dried fruit, nuts, or chocolate - Oat cakes, rye crispbread - All puddings, cakes, biscuits, and cereal bars, containing dried fruit, nuts, or chocolate	- Corn flakes, rice crispies, porridge, puffed wheat, honey coated - Wheat biscuits (in moderation) - Rice (white, risotto, and brown), barley, sago, semolina, tapioca, polenta - Flour, noodles, pasta, couscous - Bread (white, brown, whole meal), croissant, chapati, pitta bread, puri - Plain cake, biscuits, pastry (icing sugar, butter icing) - Spices; including, cinnamon, chilli powder, coriander, cumin, curry powder, ginger, mustard powder, nutmeg, pepper, turmeric - Herbs; (fresh or dried): basil (dried, ground; fresh), bay leaf, coriander leaves (fresh), coriander seeds, dill (dried; fresh), dill seeds, marjoram (dried), mint (dried; fresh), oregano (dried, ground; fresh), parsley (fresh), rosemary (fresh; dried), sage (dried, ground; fresh), tarragon (dried, ground), thyme (dried, ground; fresh); cardamom (ground), cinnamon (ground), cloves (dried), cumin seeds, curry powder, fennel seeds, ginger (fresh; ground), nutmeg (ground), pepper (black; white), saffron - Garlic, lemon juice, Tabasco, vinegar - Piccalilli, horseradish, chutney, and pickles
Condiments and flavourings - Tomato ketchup, tomato chutney, tomato puree, coconut - Meat and yeast extracts - Salt substitutes containing potassium chloride (KCl)	
Dairy, fats, and oils Yoghurts, milk puddings, custard, evaporated, and condensed milk	Cream; double, single, whipping butter, lard, vegetable oils, and margarines

12.E.1: POTASSIUM PORTIONS

Potassium portions or exchanges can be used to encourage variety. Fruits and vegetables contain potassium in varying quantities. A patient may be advised to have (daily) one portion from the potato/tuber and pulse exchange list, two portions from the vegetable list, or two portions from the fruit list. This, however, depends on biochemistry, body size, and the diet as a whole and patients may be advised to avoid certain foods in the high-potassium list.

Cooking methods such as boiling and throwing the water away will remove some potassium. Steaming, baking, stir-frying, pressure cookers, and microwaving will not remove potassium.

Potatoes, tubers, and pulses: Note that one portion contains approximately 10 mmol potassium.

150 g boiled potatoes may be replaced by:

75 g baked potato in skin or 75 g new potatoes or 75 g roast potato or 75 g boiled green banana or plantain

50 g chips (2 tablespoons) or six oven chips or two potato croquettes

150 g boiled parsnips

150 g ravioli or spaghetti in tomato sauce

150 g yam, sweet potato, dasheen, eddoes, coco yam, boiled breadfruit

150 g rice and peas (without coconut)

150 g soaked and boiled butter beans, haricot beans, black-eyed beans, baked beans in tomato sauce, dried peas, split peas, chick peas, lentils

100 g red kidney beans, boiled

Vegetables: Each portion contains approximately 5 mmol (200 mg) potassium.

Quantities are based on fresh or boiled and drained vegetables unless indicated.

High: As a guide, one portion is 75 g (1–2 tablespoons)	Medium: As a guide, one portion is 100 g (2–3 heaped tablespoons)	Low: As a guide, one portion is 150 g (3–4 heaped tablespoons)
Beetroot (boiled)	aubergine	asparagus (6 medium spears)
Brussel sprouts (6)	French beans	runner beans
fennel	broccoli	beansprouts
okra (6 pods)	celery	bamboo shoots
spinach	courgettes	cauliflower
mushrooms (boiled in water first)	curly kale	carrots
tomatoes (fresh, canned)	leeks	globe artichoke
fried onion	mangetout	red, white or Savoy cabbage
vegetable juices	capsicum / peppers (red or green)	marrow
sweetcorn kernels, on the cob or baby		pumpkin
Raw vegetables: a small portion of a mixture of salad: beetroot, red cabbage, carrots celery, chicory, coleslaw, corn kernels, cucumber, lettuce mustard and cress, peppers (red, green, yellow, or orange), radish, spring onions, tomato (no more than half a tomato), watercress	sweet-corn, fresh, or canned turnip	peas (processed, canned, frozen, mushy peas) onions boiled, pickled, or silverskin spring greens
Fruit: Each portion contains approximately 5 mmol (200 mg) potassium. Quantities are based on fresh, stewed, or canned fruit.		

High: As a guide, one portion is 50–75 g (1–2 tablespoons)	Medium: As a guide, one portion is 100 g (3 tablespoons)	Low: As a guide, one portion of fruit is 150 g (5 tablespoons)
1 fresh apricot	apricots (canned in syrup or juice)	1 apple
½ small banana	blackberries (fresh or stewed)	1 clementine
blackcurrants	12 cherries	½ grapefruit
5 dates (fresh or dried)	6–8 kumquats	a thin slice of
1 figs (fresh)	1 lemon or lime	watermelon
4 greengages (fresh)	loganberries (fresh)	1 small orange
gooseberries (fresh or stewed) grapes	6 lychees (fresh)	2 passion fruits
1 kiwi fruit	3 slices mango	1 medium-sized pear
6 prunes (dried or canned) redcurrants	melon	1 satsuma
rhubarb (stewed or canned)	1 nectarine	1 tangerine
fruit juices	paw paw (papaya)	
	1 medium peach (fresh or in	
	natural juice)	
	pineapple (1 medium thick slice)	
	2 pomegranates	
	plums: 1 large or 2 small	
	raspberries (fresh) (about 20)	
	1 sharon fruit	
	8 small strawberries	

Quality Improvement and Nursing Research in Kidney Care

Nicola Thomas

London South Bank University, London, UK

LEARNING OUTCOMES

- to explain what is meant by quality improvement (QI) and patient safety.
- to understand the process of implementing and evaluating clinical practice guidelines.
- to plan and evaluate the components of an audit of kidney care.
- to be familiar with the basic techniques in QI methodology.
- to understand where to look for research opportunities

INTRODUCTION

In 1998, the UK Secretary of State announced specific measures to ensure that ‘all patients should receive a first-class service’ (Department of Health 1998). The document in which this announcement was made highlighted that there were unacceptable variations in performance and practice, and in clinical outcomes. In England, Lord Darzi’s National Health Service (NHS) Next Stage Review report put ‘quality at the heart of everything we do’ (Department of Health 2008), whereas the more recent publication *Equity and Excellence: Liberating the NHS* commits to establishing improvement in quality and healthcare outcomes as the primary purpose of all NHS-funded care, placing patient safety ‘at the heart of the NHS’ (Department of Health 2011). In 2014, the ‘Five Year Forward View’ highlighted that unless there is a reduction in variation in quality and safety of care, then ‘patients’ changing needs will go unmet, people will be harmed who should have been cured, and unacceptable variations in outcomes will persist’ (Department of Health 2014). In 2019, the NHS Long Term Plan (NHS England 2019) was developed in partnership with those who know the NHS best – frontline health and care staff, patients and their families, and other experts.

This chapter will explore the ways in which kidney nurses can promote a high-quality service, through understanding of QI and research methods, use and evaluation of best practice guidelines, and insight into clinical audit. Nurses have a vital role to play in the promotion of quality care in kidney care and are in a key position to understand the needs of individual patients and their carers.

QUALITY IMPROVEMENT

QI has been defined as ‘the combined and unceasing efforts of everyone (healthcare professionals, patients and their families, researchers, payers, planners and educators) to make the changes that will lead to better patient outcomes (health), better system performance (care) and better professional development’ (Batalden and Davidoff 2007). Quality healthcare (Health Foundation 2013) needs to be:

- timely – reducing waits and delays.
- effective – providing services based on evidence and which produce a clear benefit.
- person-centred – establishing a partnership between practitioners and patients to ensure care respects patients’ needs and preferences.

- efficient – avoiding waste.
- equitable – providing care that does not vary in quality because of a person's characteristics.
- safe – avoiding harm to patients from care that is intended to help them.

PATIENT SAFETY

Patient safety is the avoidance of unintended or unexpected harm to people during the provision of healthcare. NHS England supports the NHS Patient Safety strategy (2019). The NHS Patient Safety Strategy sets out how the NHS will support staff and providers to share safety insights and empower people (patients and staff) with the skills, confidence, and mechanisms to improve safety. In 2023, emerging evidence showed that the NHS Patient Safety Strategy was making progress toward the impact anticipated in 2019, indicating that the strategy was halfway to achieving the aim of saving an additional 1,000 lives and £100 million per year.

The National Patient Safety Alerting Committee (NaPSAC) has been established to improve the effectiveness of safety critical communications and to support providers to better implement the required actions. One key way NaPSAC is doing this is through the introduction of National Patient Safety Alerts. For example, in 2018, there was an alert issued about management of life-threatening bleeds from arteriovenous fistulae and grafts. The alert signposted NHS Trusts to resources produced jointly by The British Renal Society (now the UK Kidney Association) and the Vascular Access Society of Britain and Ireland (VASBI) to help staff, carers, and patients recognise the warning signs.

There are two comprehensive resources available that can provide kidney nurses with practical help in addressing patient safety issues. One is NHS Impact (UK), which has a single, shared NHS improvement approach and multiple resources. NHS Impact aims to create the right conditions for continuous improvement and high performance, and to deliver better care for patients and better outcomes for communities. The other resource is the Institute for Health Improvement (USA), which aims to bring awareness of safety and quality, catalyse learning and the systematic improvement of care, develop solutions to previously intractable challenges, and mobilise health systems, communities, regions, and nations to reduce harm and deaths.

The Institute for Healthcare Improvement (IHI's) work is focused in seven key areas:

- Health equity
- Improvement capability
- Patient safety
- Whole system quality
- Workforce safety
- Workforce well-being and joy in work
- Triple aim and population health

The IHI Triple Aim and Population Health framework serves as the foundation for optimising health for individuals and populations by simultaneously improving the patient experience of care (including quality and satisfaction), improving the health of the population, and reducing cost of care for the benefit of communities.

GETTING IT RIGHT FIRST TIME (GIRFT)

This programme undertakes clinically led reviews of specialties, combining wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved. GIRFT resources include best practice pathways, case studies, and guidance documents for surgical and medical specialties as well as cross-cutting workstreams such as clinical coding and litigation.

In September 2021, GIRFT published its national speciality report for Renal Medicine (Lipkin and McKane, 2021). The report was based on insight from extensive benchmarked data as well as visits to all 52 adult renal centres in England, including the 19 transplant centres. A number of key recommendations were published (see Table 13.1) and include expanding access to home dialysis, equity and improved access to kidney transplantation, improved management of patients with acute kidney injury, improved kidney outpatient delivery, and delivering target rates for vascular access. The GIRFT report is already helping to drive improvements in care. Its recommendations have informed and are closely aligned with the 10 high-impact changes outlined by NHS England and NHS Improvement's emerging Renal Service Transformation Programme (RSTP).

CLINICAL PRACTICE GUIDELINES

Over the past 20 years, the renal specialty has seen the emergence of a number of national and international standards for renal care. When the government's way of setting

Table 13.1 GIRFT recommendations.

1. Establish NHS-funded, regional renal networks to ensure quality and efficiency of care, monitor service effectiveness, embed sustainable kidney care and accountability for service delivery.
2. Ensure that patients predicted to reach ESKD within 18 months are fully assessed in advanced kidney care services and are offered all possible care options.
3. Ensure that access to a comprehensive renal conservative management pathway is available to all patients.
4. Streamline renal transplant pathways to increase access and reduce unwarranted variation in deceased and living donor (DD and LD) transplantation.
5. Reduce variation in incident and prevalent definitive HD vascular access rates and deliver Renal Association (now UKKA) clinical practice guideline minimum thresholds.*
6. Ensure home therapy is promoted and offered for all suitable dialysis patients and that a minimum prevalent rate of 20% is achieved in every renal centre.
7. Ensure that all acute trusts implement patient safety measures to deliver highly effective prevention, detection and management of AKI.
8. Mandate clinically approved AKI patient transfer to a renal centre within 24 hours of the decision by the receiving consultant nephrologist.
9. Ensure that outpatient services are reformed in line with the NHS long-term plan to improve equity of access, patient experience, and timeliness.
10. Ensure that patient experience and shared decision-making are central to the planning and delivery of renal services.
11. Reconfigure the multi-professional renal workforce to reflect service requirements and provide optimal care, as defined throughout this GIRFT report, delivering the best outcomes and best patient experience.
12. Reduce variation and coordinate improved provision of care for patients with diabetes and ESKD.
13. Ensure that all renal centres adopt a systematic QI approach to infection prevention and control, with HD bacteraemia and PD peritonitis given equal priority.
14. Ensure that data on hospitalisation of RRT patients are available and adopted as a routine element of the quality assurance process in renal care.
15. Ensure renal centres and integrated care systems deliver effective medicines optimisation
16. Ensure that renal centres, commissioners, and patients have timely access to contemporaneous, clinically relevant outcome data, in order to support quality assurance and quality improvement.
17. Ensure that procurement of HD facilities and home therapies delivered in partnership with the independent sector offer consistent quality and cost-effectiveness across the NHS in England.
18. Reduce litigation costs through application of the GIRFT programme's five-point plan.

* 60% incident and 80% prevalent patients with AVF/G.

clear national standards was announced in 1998, the main strategy for this was through National Service Frameworks (NSF) and through a National Institute for Clinical Excellence (NICE). In early 2004 and early 2005, the NSF for Renal Services was published. This was the first NSF to be published in two parts, and although the original publications were disseminated almost one decade ago, their publication has had a tremendous impact on how renal services have developed.

In kidney care we are fortunate to have a variety of clinical standards and guidelines to help us achieve clinically effective practice. Because many of the clinical guidelines that are available have been based on research evidence or expert opinion, we do not have to examine all aspects of our care – it has already been done for us. There now follows a review of the most important clinical standards and guideline documents available for nurses working in kidney care.

NATIONAL SERVICE FRAMEWORKS

Part One of the NSF for Renal Services (Department of Health 2004) set five standards and identified 30 markers of good practice that would help the NHS and its partners manage demand, increase fairness of access, and improve choice and quality in dialysis and kidney transplant services. Part Two of the NSF for Renal Services (Department of Health 2005) set four further quality requirements and identified 23 markers of good practice. In September 2005, a summary of progress to date was published by the Department of Health (2005). In 2007, a second progress report was published, and in 2009 another report (Department of Health 2009) highlighted the successes from the previous five years.

Many related projects and documents have been published following the publication of the NSF for Renal Services. In 2013, the *Kidney Health: Delivering Excellence* (KHDE) report was published.

In 2017, the authors reviewed the 2013 KHDE report and were optimistic that the report's ambitions will continue to develop. However, some areas required further attention, including QI. As a result, a new QI ambition, Ambition 17, was added for 2017.

KIDNEY QUALITY IMPROVEMENT PARTNERSHIP

The Kidney Quality Improvement Partnership (KQuIP) is a dynamic network of kidney health professionals, patients, and carers who are committed to developing, supporting, and sharing improvement in kidney services, to enhance outcomes and quality of life for people with kidney disease. KQuIP aims to improve the lives of adults and children affected by kidney disease by supporting healthcare professionals, kidney units, kidney networks, and commissioners across the UK to achieve the highest quality of care for patients.

KQuIP builds on rather than replaces existing quality improvement structures and will help kidney services embed quality improvement into daily practice so that its part of the day job for everyone working to provide kidney services. KQuIP will help better understand and reduce unwarranted variation in standards and accessibility of care and will spread and share good practice.

The Model for Improvement (Langley et al. 2009), is a simple, yet powerful tool for accelerating improvement. The Model for Improvement implements small tests of change using Plan-Do-Study-Act (PDSA) cycles. See Figure 13.1.

An example of using PDSA in practice can be found in a KQuIP project that aimed to improve kidney transplant rates in the South-West UK (UK Kidney Association n.d.).

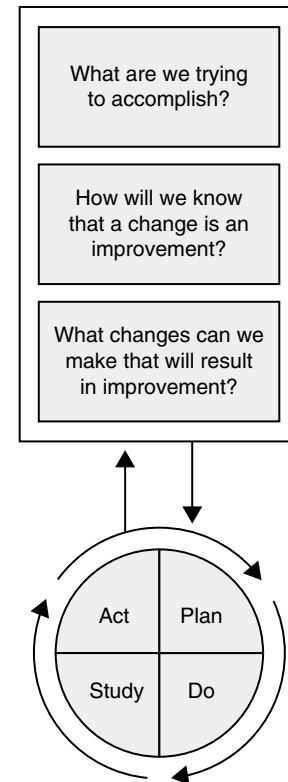


FIGURE 13.1 The model for improvement. *Source:* Institute for Healthcare Improvement (2012).

The Healthcare Quality Improvement Partnership (HQIP) was established in April 2008 to promote quality in healthcare, and in particular to increase the impact that clinical audit has on healthcare QI. HQIP is a long-term improvement partner of NHS England and has expertise in supporting kidney nurses with evidence-informed, data-driven quality improvement projects. For example, HQIP offers bespoke support, helps deliver high-quality, thoughtful insights to transform care and improve patient outcomes, and works at national, system and local levels.

NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE (NICE)

The National Institute for Health and Care Excellence produces and disseminates clinical guidelines based on relevant evidence, associated clinical audit methods, and information on good practice. NICE identifies new and existing health interventions, collects evidence, considers the implications for clinical practice, disseminates the findings, implements at a local level, and monitors the impact. The guidelines produced by NICE that are specifically relevant to kidney care practice are found in Table 13.2.

Table 13.2 Kidney-specific NICE guidance (since 2018).

Year of publication	Topic
2018	Renal replacement therapy
2019 (updated 2023)	Acute kidney injury: prevention, detection and management
2021	Chronic kidney disease: assessment and management

NICE quality standards are derived from the best available evidence and are developed independently by NICE, in collaboration with NHS and social care professionals, their partners, and service users.

The NICE quality standards are central in supporting the government’s vision for an NHS and Social Care system focused on delivering the best possible outcomes for people who use services, as detailed in the Health and Social Care Act 2012. A quality standard, *Renal Replacement Therapy (RRT)*, was published in 2014 and updated in 2018, and is shown in Box 13.1 (NICE 2018).

BOX 13.1

NICE QUALITY STATEMENTS FOR RRT (2018)

Statement 1. Adults preparing for or receiving renal replacement therapy, and their family members or carers, undertake individualised education programmes at specialist renal centres.

Statement 2. Adults who will need renal replacement therapy are offered a pre-emptive kidney transplant, if they are medically suitable.

Statement 3. Adults on dialysis are offered a kidney transplant, if they are medically suitable.

Statement 4 This statement was removed in 2018.

Statement 5. Adults who need long-term dialysis are offered home-based dialysis.

Statement 6 This statement was removed in 2018.

Statement 7. Adults who have a suspected acute rejection episode have a transplant kidney biopsy carried out and reported on within 24 hours.

Statement 8. Adults receiving haemodialysis have their vascular access monitored and maintained using systematic assessment.

Source: National Institute for Health and Care Excellence (2018).

EUROPEAN STANDARDS FOR NEPHROLOGY NURSING PRACTICE

In 1990, the European Dialysis and Transplant Nurses’ Association/European Renal Care Association (EDTNA/ERCA) commenced work on writing European clinical standards and in 1995 published European Standards for Nephrology Nursing Practice (Van Waeleghem and Edwards 1995). This document was published alongside the European Core Curriculum for a post-basic course in nephrology nursing, which was updated in 2022 (Sedgewick, McCann and Thomas 2022). These standards were one of the first publications that recommended specific guidelines for kidney nursing practice.

KIDNEY DISEASE OUTCOME QUALITY INITIATIVE/KIDNEY DISEASE IMPROVING GLOBAL OUTCOMES

In recent years, kidney nurses have had access to a variety of multi-professional best practice guidelines. KDOQI (Kidney Disease Outcome Quality Initiative, originally called DOQI or Dialysis Outcome Quality Initiative) provides evidence-based clinical practice guidelines developed by volunteer physicians and healthcare providers for all stages of CKD and related complications, from diagnosis to monitoring and management. KDOQI guidelines not only address dialysis but all stages of CKD. The first set of guidelines developed by KDOQI on the evaluation, classification, and stratification of CKD was published in February 2002.

The name under which the initiative is now incorporated is ‘Kidney Disease: Improving Global Outcomes’ (KDIGO). KDIGO is a global nonprofit organisation developing and implementing evidence-based clinical practice guidelines in kidney disease. KDIGO is governed by a volunteer Executive Committee made up of leading nephrology experts from around the globe, who make critical decisions about KDIGO priorities, projects, and resource allocations.

Since the original development of the DOQI guidelines in haemodialysis and peritoneal dialysis, there have been developments in certain areas of care, such as blood pressure (2021), diabetes (2022), and hepatitis C (2022). For further information, visit the homepage (see Resources section).

UK KIDNEY ASSOCIATION

From mid-2006, the Clinical Practice Guidelines of the UK Renal Association (now UK Kidney Association) were published in modular form. Table 13.3 shows current and upcoming modules and expected review date.

Table 13.3 UK Kidney Association clinical practice guidelines.

Module	Date	Review due
Acute kidney injury	2019	2024
Anaemia in chronic kidney disease (CKD)	2020	2022
Blood-borne viruses	2019	2024
Exercise and lifestyle in CKD	2021	2026
Haemodialysis	2019	2024
Living kidney donor	2018	2023
Pregnancy in CKD	2019	2024
Peritoneal dialysis	2017	2023
Postoperative care of the kidney transplant recipient	2017	2023
Vascular access for haemodialysis	2023	2028
Undernutrition in CKD	2019	2024

Source: Adapted from UK Kidney Association clinical guidelines (see Resources section).

OTHER GUIDELINES

A variety of clinical practice guidelines are available including those developed or endorsed by European Best Practice (EBPG). The primary mission of EBPG is to ‘improve the outcome of patients with kidney disease in a sustainable way by enhancing the availability of knowledge on the management of these patients in a format that stimulates its use in clinical practice in Europe’. To accomplish this mission, EBPG disseminates, endorses, and stimulates implementation and translation of guidelines in kidney disease following collaboration with other guideline development groups.

The International Society of Peritoneal Dialysis (ISPD) also produces international clinical guidance on PD.

EVALUATION OF GUIDELINES

There are numerous local, national, and international guidelines that kidney nurses can access for achieving clinically effective practice. It is helpful to have a checklist to evaluate how useful guidelines are to a local renal nursing team. The following questions could be used for evaluation:

- Are the guidelines based on evidence, expert opinion, or both?
- What is the quality of the evidence? (Does it consist of well-conducted clinical studies, reports, opinions, and clinical experience of respected professionals?)
- Are the guidelines specific enough?

- Are the guidelines local, national, or international?
- Have patients been involved in the development?
- Do the guidelines cover nursing care and measure nursing impact?

The last point is difficult to evaluate as, of course, nurses do not work in isolation and therefore all members of the multiprofessional team contribute to patient outcome. But it is important that nurses recognise that it is nursing that they have to measure, and not necessarily the easier-to-measure variables such as blood pressure, potassium level, Kt/V , and haemoglobin levels. What matters to patients is the depth of the communication, the skill of the teaching, and the quality of their life, and although it is recognised that all of these are very difficult to measure, nurses must strive to evaluate these as part of the audit process.

AUDIT

The National Institute for Health and Care Excellence (NICE) provides numerous resources to help with planning ahead for NICE guidance, understanding where you are now, and conducting improvement initiatives. NICE provides a library of clinical audit tools which can be used to improve care. They contain clinical audit standards based on NICE guidance (published before June 2015). NICE audit tools contain the following:

- A data collection sheet
- A clinical audit report that provides basic information about the audit and automatically displays the audit results
- An action plan template
- An appendix containing a printable data collection form

The aim of a clinical audit is to make the process of developing clinical audit projects easier through the provision of ready-to-use criteria, including exceptions, definitions, and data source suggestions. One example is the suggestions for clinical audit that accompany the clinical guideline on chronic kidney disease. Here you can review clinical audit tools and other resources to put the guidelines into practice and improve patient care (NICE 2021).

KIDNEY NURSING RESEARCH

The opportunities for kidney nurses to engage in clinical research are increasing year-on-year. Research is the cornerstone of high-quality, evidence-based nursing. The

Chief Nursing Officer (CNO) for England's strategic plan for research sets out the ambition to "create a people-centred research environment that empowers nurses to lead, participate in and deliver research, where research is fully embedded in practice and professional decision-making, for public benefit" (NHS England 2021).

Five themes underpin this ambition:

- Aligning nurse-led research with public need
- Releasing nurses' research potential
- Building the best research system
- Developing future nurse leaders of research
- Digitally enabled nurse-led research

Further explanation of each theme is beyond the scope of this textbook, but the webpage (see Resources section below) summarises planned activities that start turning the plan into reality. Kidney nurses looking for research opportunities could contact their research and development department in their local hospital, be in touch with the nursing department in their local university, explore opportunities with the National Institute for Health Research (NIHR), or become a member of the Association of Nephrology Nurses (ANN UK). The Royal College of Nursing provides a useful list of funding opportunities, plus a fortnightly research and innovation bulletin. See Resources section below.

ASSOCIATION OF NEPHROLOGY NURSES UK (ANN UK)

ANN UK is a national community for kidney nurses. This national association (with overseas membership possible)

provides numerous opportunities for support, learning, and networking. ANN UK also has a useful resources page that gives key links to evidence-based clinical guidelines, policies, patient safety and patient information, workforce planning documents, and prescribing information so kidney nurses can locate relevant QI and research information in one place (see Resources below).

Clinical research is one of the fastest-growing specialties in healthcare delivery, with the NHS being seen as an international leader. The aim of the ANN UK Nursing Research in Kidney Care Community of Practice (COP) is to promote the voice of kidney nursing research whilst creating a national network and forum to further the influence of nurses working in kidney care research across the UK. The COP develops and shares best clinical and research practice, informs and enhances the care of patients with kidney disease participating in research studies, and creates a network of kidney nurses to encourage collaborative working and career development.

To join ANN UK and the Research COP, visit their webpage.

CONCLUSION

Increasingly, kidney nurses are being asked to identify and implement ways to improve the quality of care they provide. There are now a wide variety of resources available to help them, including those from NHS Impact, the IHI, and KQuIP. However, it is important to remember that patients must be at the centre of any QI or research intervention and must also be included in the planning phase. Kidney nurses are increasingly contributing to the culture of continuous QI and also research in patient care and have a very important role to play in patient safety initiatives.

REFERENCES

- Batalden, P.B. and Davidoff, F. (2007). What is quality improvement- and how can it transform healthcare? *Quality and Safety in Health Care* 16 (1): 2-3.
- Department of Health (1998). *A First Class Service. Quality in the New NHS*. London: HMSO.
- Department of Health (2004). *National Service Framework for Renal Services – Part 1 Dialysis and Transplantation*. London: HMSO.
- Department of Health (2005). *National Service Framework for Renal Services – Part 2*. London: HMSO.
- Department of Health (2008). *High Quality Care for All: NHS Next Stage Review Final Report*. London: Department of Health.
- Department of Health (2009). *Renal National Service Framework Updated*. London: HMSO.
- Department of Health (2011). *Equity and Excellence: Liberating the NHS*. London: Department of Health.
- Department of Health (2014). *Five Year Forward View*. London: Department of Health.
- Health Foundation (2013). *Quality Improvement Made Simple*. London: Health Foundation.
- Institute for Healthcare Improvement (2012). The 'model for improvement' in *How to Improve*, Massachusetts: Institute for Healthcare Improvement (available on www.ihl.org).

- Institute for Healthcare Improvement (2024). <http://www.ihl.org> (accessed 12 February 2024).
- Kidney Health Partnership Board. (2017). *Kidney Health: Delivering Excellence*.
- Kuentzle, W. and Thomas, N. (eds.) (1995). *European Core Curriculum for a Post-Basic Course in Nephrology Nursing*. Ghent, Belgium: European Dialysis and Transplant Nurses Association/European Renal Care Association.
- Langley, G.L., Nolan, K.M., Nolan, T.W. et al. (2009). *The Improvement Guide: A Practical Approach to Enhancing Organizational Performance*, 2e. San Francisco: Jossey-Bass.
- Lipkin, G and McKane, W (2021) Renal Medicine: GIRFT Programme National Specialty Report. <https://gettingitrightfirsttime.co.uk/wp-content/uploads/2021/09/Renal-Medicine-Sept21k.pdf> (accessed 12 February 2024).
- NHS England (2019) The NHS Long-term Plan <https://www.england.nhs.uk/wp-content/uploads/2022/07/nhs-long-term-plan-version-1.2.pdf> (accessed 24 February 2024).
- NHS England (2019) Patient Safety strategy. https://www.england.nhs.uk/wp-content/uploads/2020/08/190708_Patient_Safety_Strategy_for_website_v4.pdf (accessed 12 February 2024).
- NHS England (2021) Chief Nursing Officer for England's strategic plan for research. <https://www.england.nhs.uk/nursingmidwifery/research-and-evidence/> (accessed 24 February 2024).
- NHS Impact (2023) <https://www.england.nhs.uk/nhsimpact/> (accessed 12 February 2024).
- National Institute for Health and Care Excellence (NICE) (2021). Chronic kidney disease: assessment and management. <https://www.nice.org.uk/guidance/ng203/resources> (accessed 24 February 2024).
- National Institute for Health and Care Excellence (NICE) (2018). Renal replacement therapy services for adults, quality standard. <https://www.nice.org.uk/guidance/qs72> (accessed 24 February 2024).
- Sedgewick, J. McCann, M., and Thomas, N. (2022) (3rd ed.) *The European Core Curriculum for a Post-Basic Course in Nephrology Nursing*. EDTNA/ERCA, Switzerland.
- UK Kidney Association (n.d.). KQuIP. Improving kidney transplant rates in the South West through kidney quality improvement partnership. <https://ukkidney.org/kquip/improving-kidney-transplant-rates-south-west-through-kidney-quality-improvement-partnership> (access 24 February 2024).
- Van Waeleghem, J.P. and Edwards, P. (1995). *European Standards for Nephrology Nursing Practice*. Ghent, Belgium: European Dialysis and Transplant Nurses Association/European Renal Care Association.

RESOURCES

- Association of Nephrology Nurses <https://ann-uk.org/> (accessed 24 February 2024)
- European Best Practice <https://www.era-online.org/about-us/committees/erbep-european-renal-best-practice> (accessed 24 February 2024)
- HQIP <https://www.hqip.org.uk/> (accessed 24 February 2024)
- International Society of Peritoneal Dialysis <https://ispd.org/guidelines/> (accessed 24 February 2024)
- KDIGO <https://kdigo.org/> (accessed 24 February 2024)
- KQuIP <https://ukkidney.org/kquip/homepage> (accessed 12 February 2024)
- National Institute for Health Research (NIHR) <https://www.nihr.ac.uk/health-and-care-professionals/engagement-and-participation-in-research/> (accessed 24 February 2024)
- NHS England <https://www.england.nhs.uk/nursingmidwifery/research-and-evidence/> (accessed 24 February 2024)
- NICE <https://www.nice.org.uk/guidance> (accessed 12 February 2024)
- Royal College of Nursing <https://www.rcn.org.uk/professional-development/research-and-innovation/research-funding-opportunities> (accessed 24 February 2024)
- UK Kidney Association <https://ukkidney.org/health-professionals/guidelines/guidelines-commentaries> (accessed 24 February 2024)

Note: page numbers in *italics* refer to figures; those in **bold** to tables.

A

ABMR. *see* antibody-mediated rejection (ABMR)

ABO blood groups, 227, 228

Academy of Medical Royal Colleges, 237

acetate

electrolytes, 157

HD prescription, 157, 158

acid-base balance in stage 4 CKD, control of, 140–141

acidosis

dietary management of, 297

metabolic. *see* metabolic acidosis

Acute Dialysis Quality Initiative (ADQI), 121

acute interstitial nephritis, AKI related to, 119

acute kidney injury (AKI), 115–129

causes of AKI

acute interstitial nephritis, 119

acute liver injury, 119–120

ATN, 120

cortical necrosis, 120

identification of, 124

nephrotoxicity, **120**, 120–121

post-renal failure, 121

pre-renal renal failure, *118*, 118–119

renal failure, **117**, 119–121

rhabdomyolysis, 119

children, 282–283. *see also* children, AKI

CKD and, 115

clinical course of, 124, **125**

costs related to, 115

hyperkalaemia and, 122–123

introduction, 115–129, *116*, 117, 118, **120–121**

KRT for, 115–116, 124–128, *126–128*, 283

management of, 122

hyperkalaemia-related, 122–123

infection-related, 124

metabolic acidosis-related, 123

nutrition, 123–124

sepsis-related, 124

uraemia-related, 123

urological obstruction-related, 122

volume overload-related, 123

mortality related to, 116–117

NCEPOD on, 115

NICE on, 116, 124

prevention of, 122

signs and symptoms of, 116, *116*

stages of, 124–125, **125**

Acute Kidney Injury Network (AKIN), 122, **122**

acute liver injury, AKI related to, 119–120

acute peritoneal dialysis (PD), AKI, 127

acute rejection, 250–252, *251*

acute tubular necrosis (ATN), 236

after renal transplantation, 254

AKI related to, 120

adolescence, renal disease during transition to adult services, 284

ADQI. *see* Acute Dialysis Quality Initiative (ADQI)

advanced kidney disease (AKD)

dietary management of, 288–312. *see also* dietary interventions

renal transplantation for, 309–311

advance planning, palliative care, 266–267

Advisory Committee for European Best Practice Guidelines, 210

age as factor, renal transplantation, 222, 223

air embolism, during HD, 178–179, *179*

AKD. *see* advanced kidney disease (AKD)

AKI. *see* acute kidney injury (AKI)

AKIN. *see* Acute Kidney Injury Network (AKIN)

Allis-Chalmers Corporation, 3–4

altruism, living relation donation, 238

American Society for Artificial Internal Organs, 8

anaemia

dietary management of, 296–297

management of, 277

stage 4 CKD, 138

anaemia investigations, 42

ferritin, 42–43

haematinics, 42

red-cell folate, 43

serum iron, 43

transferrin saturation rate, 43
 vitamin B₁₂, 43
 “analgesic ladder” of WHO, 269
 AN69 ST membrane, 158
 antibiotics, prophylactic, 196
 antibodies, T-cell depleting, 248
 antibody-mediated rejection (ABMR), 250, 251
 anticoagulation, HD, 165–168, 167
 within extracorporeal circuit, 166–167
 HIT related to, 166–167
 antigen(s)
 histocompatibility, 227
 human leukocyte, 226, 228
 transplant, 226
 antiproliferative agents, maintenance immunosuppression, 249
 anxiety, pre-renal transplant-related, 224
 APD. *see* automated peritoneal dialysis (APD)
 area puncture, AVF and AVG function preservation, 173, 174
 arteriovenous fistula (AVF)
 for HD, 168, 168–169, 169
 vascular access
 cannulation techniques, 171–174,
 173–174
 care of, 171
 arteriovenous graft (AVG)
 for HD, 168, 168–169, 169
 vascular access
 cannulation techniques, 171–174,
 173–174
 care of, 171
 artificial kidney, history of, 1–2
 Austin Diagnostic Clinic, 8
 automated peritoneal dialysis (APD), 200, **202**
 history of, 9
 peritonitis resulting from obtaining effluent specimen, 210–211
 AVF. *see* arteriovenous fistula (AVF)
 AVG. *see* arteriovenous graft (AVG)
 azathioprine, maintenance immunosuppression, 249

B

bacterial infections, after renal transplantation, 254
 BAPEN. *see* British Association for Parenteral and Enteral Nutrition (BAPEN)
 Bartter’s syndrome, 276
 base fluctuations, healthy individual
 fall, plasma pH, 28
 rise, plasma pH, 28–29
 basiliximab, immunosuppression induction, 248
 BDA. *see* British Dietetic Association (BDA)
 belatacept, immunosuppression, 250
 Belzer, 10
 bicarbonate
 based solutions PD, 204
 buffering system, 26
 HD prescription, 157–158
 bilateral nephrectomy technique, 235–236, 236

biochemical blood tests
 albumin, 40
 bicarbonate, 40
 complement, 40
 creatinine kinase, 40
 glycosylated haemoglobin, 40
 immunoglobulins, 41
 lipids, 40
 measuring glucose, 40
 plasma total protein, 40
 serology, 40
 uric acid, 40
 viral serology, 41
 biopsy, transplant, 252
 BK (polyoma) virus, after renal transplantation, 255
 blood flow rate (BFR), improving HD clearance, 159–160
 blood glucose, control of, 203
 blood pressure
 control, 29
 management of, 276–277
 blood-stained effluent, PD, 209
 blood supply during PD, 190
 blood volume
 calculation, HD, 282
 monitoring, 165
 BMI. *see* body mass index (BMI)
 body composition
 assessment of
 hypoalbuminaemia, 305
 malnutrition-related, 306–307
 PEW, 306
 renal-specific formulae, 308
 SGA, 305–306
 techniques, 304–309
 changes, 297
 body mass index (BMI), 75
 body composition assessment, 304
 calculation of, 318
 bone disease
 after renal transplantation, 310
 stage 4 CKD, management of, 138–139
 bone health, management of, 277–278
 brain stem death
 causes of, 229–230
 declaration of, 230
 diagnosis of, 230
 time of, 230
 brain stem, functions of, 229–230
 British Association for Parenteral and Enteral Nutrition (BAPEN), 303
 British Dietetic Association (BDA), 296
 Renal Nutrition Group of, 289
 British Hypertension Society, 277
 British Royal Society, Vascular Access Special Interest Group of, 170
 British Transplant Society, 240
 buttonhole technique, AVF and AVG function preservation, 172–173,
 173, 174

C

- CAI. *see* chronic allograft injury (CAI)
- calcineurin inhibitors, maintenance, immunosuppression, 248–249
- calcitriol, 39
- calcium, 39
- acetate, 158
 - metabolism of, dietary management of, 294
 - resonium, 296
- Canada-USA (CANUSA) Peritoneal Dialysis Study Group, 305, 306
- cannulation techniques
- area puncture, 173, 174
 - AVF and AVG function preservation, 171–174, 173–174
 - buttonhole technique, 172–173, 173, 174
 - correct needle placement, 175
 - by experienced and well-trained nurses, 175
 - gentleness and sensitivity, 175
 - planning of, 174–175
 - procedure guidelines, 174
 - rope ladder technique, 173–174, 174
 - self-awareness of cannulator, 175
 - tourniquet use, 175
- CANUSA Peritoneal Dialysis Study Group, 305
- CAPD. *see* continuous ambulatory peritoneal dialysis (CAPD)
- capillary endothelium, 190, 191
- capillary-flow dialyser, 4
- cardiac disease, evaluation for renal transplantation, 223
- cardiovascular disease (CVD)
- after renal transplantation, 309–310
 - as contraindication to renal transplantation, 223
 - risk factors for, dietary interventions, 291–292
- cardiovascular risk management, stage 3a–3b CKD, 136
- care
- patient involvement, 52–53
 - PD
 - malpositioned, 208
 - Swan-neck, 195, 195
 - post-operative care of kidney transplant recipients, 252
 - Tenckhoff, 7–8, 195, 195
- Care Quality Commission in England, 52–53
- carer, thoughts of, 57–58
- advanced kidney disease, 58
 - home haemodialysis, 59
 - hospital-based haemodialysis, 58–59
 - post-transplant follow-up, 60
 - thoughts to you as nurses, 60
 - transplantation, 58, 59–60
- CARI. *see* Caring for Australians with Renal Impairment (CARI)
- Caring for Australians with Renal Impairment (CARI), 294
- catheter(s). *see also* specific types central venous
- for HD, 169, 169
- central nervous system (CNS) disorders, stage 4 CKD, 141
- central venous catheters (CVCs)
- for HD, 169, 169
 - tunnelled. *see* tunnelled central venous catheters (TCVCs) care
- childhood. *see also* children
- physiology, impact on renal care, 274–275, 275
 - renal disease, 274
- children. *see also* childhood
- AKI, 282–283
 - causes of, 283
 - conservative management of, 276
 - described, 282–283
 - treatment of, 283
 - atypical HUS, 284
 - biochemistry reference ranges for, 275, 275
 - CKD, 275, 275–276
 - conservative management of, 276
 - dietary interventions for, 311
 - dialysis, 281–282
 - HD, 281–282
 - PD, 281, 282
 - preparation for, 281
 - fluid balance, 275
 - growth, 275
 - HUS, 284
 - immunosuppressed immunisation for, 280
 - NS, 278–279. *see also* nephrotic syndrome (NS), children
 - renal anatomy, 275, 275
 - renal care of, 274–284
 - renal disease, 275
 - renal transplantation for, 279–281
 - care after, 280
 - complications following, 280
 - immunosuppression after, 280
 - living donor transplantation, 279
 - LRD, 279
 - pre-emptive transplantation, 279–280
 - preparation for, 280, 281
 - RRT, 279–281
- chronic allograft injury (CAI), 252
- chronic conditions (CCs), 71
- chronic kidney disease (CKD)
- children
 - conservative management of, 276
 - dietary interventions for, 311
 - presenting symptoms, 275, 276
 - classification of, 117, 117–118, 121–122, 121–122
 - dialysis for, 142
 - dietary treatment of, 290
 - management, primary care
 - clinical guidelines for, 135
 - innovation, 135–136
 - mild to moderate, management, primary care, 135
 - predialysis phase of, education, 142
 - referral for, 137
 - stage 3a–3b
 - AKI and, 115

cardiovascular risk management, 132–145, 135
 care and management of, 136, 137
 children, **275**, 275–276
 described, 132
 diabetes mellitus and, 132, 137
 diagnosis explaining, 136
 explaining diagnosis, 136
 GMS contract for, 134
 infertility and impotence related
 to, 141
 introduction, 132
 K/DOQI classification of, 134
 medicines review, 137
 monitoring of, 136–137
 PDEPs for, 142, 145
 prevalence of, 132, 262
 referral for, 137
 Renal Association e-guide for, 135
 self-management of, 136–137
 stage 4
 acid-base balance, 140–141
 anaemia control, 139
 bone disease management, 138–139
 care and management of, 137–141
 CNS disorders, 141
 control of serum bicarbonate within normal levels, 138
 dermatological disorders management, 139–140
 gastrointestinal disorders control, 139
 nutrition, management of, 138
 potassium disorders control, 140
 sexual function problems, 141
 volume disorders control, 140
 stage 5
 staging of, 134
 symptoms experienced, 267–268
 Chronic Renal Insufficiency Cohort (CRIC) study, 75
 ciclosporin, 10
 circulatory death, donation after, 236–237
 CKD. *see* chronic kidney disease (CKD)
 CKD Audit, 132
 Clinical Lead in Organ Donation (CLOD), 244
 CLOD. *see* Clinical Lead in Organ Donation (CLOD)
 Clotting, HD, 165–168, 167
 CMV. *see* cytomegalovirus (CMV)
 CNS. *see* central nervous system (CNS)
 cold ischaemia, deceased donation, 236
 collodion, 1
 communication, palliative care
 family-related, 265–266
 patient-related, 264–265
 team-related, 266
 computed axial tomography/ computed tomography
 (CAT/CT) scan, 48
 conservative management (CM), 71

constipation
 end-of-life care related to, 267–268
 PD, 208
 continuing care, post-operative care of renal transplant
 recipients, 253–254
 continuous ambulatory peritoneal dialysis (CAPD), **189**, 189–190, **202**
 FDA on, 8
 history of, 1, 8
 peritonitis resulting from obtaining effluent specimen, 210–211
 as portable/wearable equilibrium dialysis, 8
 continuous cycling peritoneal dialysis (CCPD), 8, 200, 200
 continuous haemodiafiltration (HDF) AKI, 127, 127
 continuous haemodialysis (HD), AKI, 127, 128
 continuous haemofiltration (HF), AKI, 126, 126
 continuous kidney replacement therapy (CKRT) for AKI,
 116, 124–126
 convection
 HD, 152, 152
 PD, 192
 coroner, organ donation permission
 from, 235
 cortical necrosis, AKI related to, 120
 corticosteroids, maintenance immunosuppression, 249–250
 COVID-19, and KD, 71–73
 creatinine, 38
 PD adequacy assessment, 205
 cross-match, pretransplant, 228
 Cuprophane, 4
 CVC(s). *see* central venous catheters (CVCs)
 CVD. *see* cardiovascular disease (CVD)
 cytomegalovirus (CMV) after renal transplantation, 255

D

Dacron cuff, 7
 DBD. *see* Donation after Brainstem Death (DBD)
 DCCT. *see* Diabetes Control and Complications Trial (DCCT)
 DCD. *see* Donation after Circulatory Death (DCD)
 DDS. *see* dialysis disequilibrium syndrome (DDS)
 deceased donation, 229–237, 236
 acceptance that death has occurred, 232
 after circulatory death, 236–237
 brain stem death, causes of, 229, 230
 brain stem functions, 229–230
 clinical care of potential organ donor, 234
 cold ischaemia, 236
 continuing care after donation, 233
 contraindications to, 230–231
 DBD vs. DCD, 229
 fear of increasing distress of family, 232
 how to offer donation, 233
 organisation of organ donation procedure and surgery, 234
 organ preservation, 236
 permission from coroner, 235
 refusal to donate, 233–234

- deceased donation (*cont'd*)
 - religious beliefs, 231–232
 - removal of kidneys from multiorgan donor, 235
 - for renal transplant, 226–237, 236
 - requesting donation, 231–234
 - SNOD's role, 234
 - surgical technique for deceased donor nephrectomy, 235–236, 236
 - unconditional gift, 233
 - warm ischaemia, 236
 - when to offer donation, 233
 - who should offer donation, 233
- deceased donation nephrectomy technique, 235–236, 236
- decision making, dialysis-related, palliative care, 266
- definitive access provision, vascular access for HD, 170, 171
- Department of Health, 243, 329
- dermatological disorders, 139–140
- DEXA scan, body composition assessment, 305
- Diabetes Control and Complications Trial (DCCT), 293
- diabetes mellitus
 - after renal transplantation, 310–311
 - CKD and, 132, 138
 - as contraindication to renal transplantation, 222
 - dietary interventions for, 289
 - HD and, 180–181
 - pathologies associated with, 49
 - PD for patients with, 202. *see also* peritoneal dialysis (PD), for diabetes patients
- Diabetes UK guidelines, 293–294
- diabetic kidney disease, 33
 - pathology, 33
- dialysate
 - components of, 157, 157–158
 - flow rate of, 160
 - HD prescription, 157, 157–158. *see also* haemodialysis (HD) prescription
 - temperature of, 165
- dialysate fluid, 149, 149
- dialyser(s). *see also* specific types
 - capillary-flow, 4
 - clotting, 161
 - development of, 1–11
 - HD, 148–149, 149, 150, 158
 - Kiil, 4, 5
 - Kolff, 3–4
 - parallel, 4
 - size of, 159–160
- dialysis
 - children, 281–282
 - for CKD, 142
 - described, 148
 - dietary management during, 299–302, 300. *see also* dietary interventions, dialysis-related
 - history of, 1–11. *see also* specific types, e.g., haemodialysis
 - introduction, 148
 - modality for, 154, 154–157
 - nutritional health of patient prior to NIH on, 288
 - patient undergoing, 53
 - advanced kidney care, 54
 - best practice and peer review, 56
 - cannulation protocols, 55
 - care as inpatient, 57
 - communication and empowerment, 54–55
 - holidays, 55
 - home dialysis, 55–56
 - infection control, 55
 - monitoring, 55
 - outpatient care and immunosuppression, 57
 - patient choice and shared decision-making, 56
 - transplantation, 56
 - peritoneal. *see* peritoneal dialysis (PD)
 - pre-operative, 245
 - single-needle vs. double-needle, improving HD clearance, 160–161
- dialysis decision-making, palliative care, 266
- dialysis disequilibrium syndrome (DDS), 179, 179
- dialysis modality. *see also* haemodialysis (HD) prescription, dialysis modality
 - HD prescription, 153–157, 154
- Dialysis Outcome Quality Initiative (DOQI), 289, 330
- Dialysis Outcomes and Practice Patterns Study (DOPPS), 154, 169–170, 302
- diet(s)
 - Giovanetti, 288
 - management of CKD and AKI, children, 276
 - Mediterranean, 293
 - VLPD, 288
- dietary interventions, 288–312
 - for acidosis, 297
 - for AKD, 288–312
 - for anaemia, 296–297
 - calcium-related, 294
 - cardiovascular risk-related, 292–293
 - for children, 311
 - for CKD, 290
 - for diabetes, 293–294
 - dialysis-related, 299–302, 300
 - current concepts of, 289–290, 290
 - energy requirements, 291, 300
 - historical review, 299
 - minerals, 302
 - phosphorus, 300, 302
 - potassium, 300, 302
 - protein, 299, 300
 - sodium and fluid requirements, 301
 - vitamin(s), 300, 302
 - historical review of, 288–289

- for hyperkalaemia, 295–296
 - for hyperlipidaemia, 292–293
 - for hypertension, 292
 - for malnutrition, 297–298. *see also* malnutrition
 - for NS, 298, **299**
 - predialysis
 - current concepts on, 289–92, 290
 - for renal transplant recipients, 310–311
 - for RRT patients, 299, 300
 - Dietetic (Nutrition) Care Process, 306
 - diffusion
 - HD, 151, 151–152
 - PD, 191–192, 192
 - Donation after Brainstem Death (DBD), 229
 - Donation after Circulatory Death (DCD), 229
 - donor and recipient matching, LRD, 240
 - donor organs
 - increasing supply of, 243–244, **244**
 - legislation, 244
 - Doolan technique, 7
 - DOPPS. *see* Dialysis Outcomes and Practice Patterns Study (DOPPS)
 - DOQI. *see* Dialysis Outcome
 - drainage problems, PD, 208
 - dry weight assessment, fluid removal, 161–162, 162
 - dual-energy x-ray absorptiometry (DEXA) scan, body composition assessment, 305
 - Dubost, 9
 - Dyspnoea, 270
- E**
- East London Community Kidney Service, 135, 137
 - “Eat Well Guide,” 311
 - EBPG. *see* European Best Practice Guidelines (EBPG)
 - EDTNA/ERCA. *see* European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA)
 - education
 - kidney nursing, patient and carer involvement, 61
 - for PD patients, 214–217
 - predialysis phase of CKD, 142
 - electrolyte(s), acetate, 157
 - embolism, air, 178–179, 179
 - emotional support
 - living donation, 243
 - pre-operative management of renal transplant recipients, 246
 - emotional well-being, 67–104
 - caregivers’ role, 103–104
 - CKD
 - and mental illness, 77–78
 - and severe mental illness, 78–79
 - cognitive impairment, 79
 - conservative kidney management, 98–99
 - COVID-19 and KD, 71–73
 - depression, 99–100
 - description of, 67–104
 - food and fuel banks, 75–76
 - haemodialysis (HD), 86–90
 - health inequalities, kidney disease, 73
 - health literacy, 77
 - home dialysis, 90
 - home haemodialysis (HHD), 90–91
 - individual symptom management, 83–85, **84**
 - introduction, 67–71
 - kidney management, conservative, 98–99
 - kidney transplantation (KT), 93–94
 - kidney transplant, failing, 97–98
 - lesbian, gay, bisexual, transgender, and queer (LGBTQ+) communities, 79–80
 - life participation, 81–82, 82
 - living donor kidney transplant (LDKT), 94–95
 - patient activation, 82–83
 - peritoneal dialysis (PD), 91–93
 - post-kidney transplant, 95–97, **97**
 - QOL and living well with kidney disease, 80–81
 - sexuality, 101–103, **102**
 - social deprivation, 73–75
 - stable housing, 76
 - strengths-based approach, 85–86, **85–86**
 - encapsulating peritoneal sclerosis (EPS), 207
 - end of life
 - management of, 267–268
 - symptoms toward, 267–270
 - assessment of, 267–268
 - described, 267
 - end-of-life care. *see also* palliative care
 - spirituality, 271
 - End-of-Life Care Strategy, 264
 - endothelium, capillary, 190, 191
 - end-stage kidney disease (ESKD), 74, 132
 - as cost-effective care, 220
 - PD for, 189
 - renal transplantation for, 220
 - end-stage renal disease (ERD), children, 275, **275**
 - energy, lack of, 269
 - energy requirements
 - degree of renal function vs., 289
 - dialysis patients, 299, 300
 - nutrition-related, 290–292
 - eosinophil(s), WBC count, 158
 - EPS. *see* encapsulating peritoneal sclerosis (EPS)
 - Equity and Excellence: Liberating the NHS, 326
 - erythropoietic stimulating agents (ESAs), anaemia control, stage 4, 139
 - ESAs. *see* erythropoietic stimulating agents (ESAs)
 - ESKD. *see* end-stage kidney disease (ESKD)
 - established renal failure (ERF), vitamins for patients with, 302

estimated glomerular filtration rate (eGFR), 46
 Cystatin C, 46
 kidney function assessment, 133
 ethical issues, living relation
 donation-related, 237
 European Best Practice Guidelines (EBPG), 331
 European Dialysis and Transplant Nurses Association/European
 Renal Care Association (EDTNA/ERCA), 289, 330
 European Standards for Nephrology Nursing Practice, 330
 EU Tissue and Cells Directive, 239
 11th Evacuation Hospital, Korea-8, 5
 everolimus, maintenance immunosuppression, 250
 exit-site infection, PD and, 213–214
 extracorporeal circuit, HD, 149–150, 150
 clotting management-related, 166–167

F

family communication, palliative care, 265
 fatigue, end-of-life care related to, 269
 FDA. *see* Food and Drug Administration (FDA)
 fear(s), pre-renal transplant-related, 224, 226
 FHN. *see* Frequent Hemodialysis Network (FHN)
 FHN Trial, 155
 fibrin formation, PD, 208
 fistula(s), arteriovenous *see* arteriovenous fistula (AVF)
 “Five Year Forward View,” 326
 flow problems, prevention of, 216
 fluid(s)
 balance, 243, 275
 dialysate, 150, 150
 dialysis patients, 301
 loss, 162–163, 163
 management of CKD and AKI, children, 276
 PD, 203
 removal, 161–162, 162
 Food and Drug Administration (FDA) on CAPD, 8
 food banks, 75–76
 Food Standards Agency (FSA) guidelines, 292
 Frequent Hemodialysis Network (FHN), 155, 156
 FSA. *see* Food Standards Agency (FSA)
 fuel banks, 75–76
 fungal infections after renal transplantation, 254
 fungal peritonitis, PD and, 213

G

Galen, 6
 gastrointestinal disorders, stage 4 CKD, 139
 General Medical Council (GMC), 231
 Giovanetti diet, 288
 glomerular filtration, 18, 18–20, 19
 estimated glomerular filtration rate (eGFR), 20
 glomerular filtration rate (GFR), kidney function and, 133
 glomerulonephritis, 33–34
 crescentic, 35

 focal segmental, 35
 membranous, 34–35
 mesangial, 35
 mesangiocapillary or membrane-proliferative, 35
 minimal-change, 34
 post-infection, 35
 subtypes of, 34
 glucose-based solutions, PD, 203–204
 glucose fluid(s), acetate, 157
 GMC. *see* General Medical Council (GMC)
 growth, factors influencing, 275
 Guthrie, 9
 Guy's Hospital, 227

H

HADS. *see* Hospital Anxiety and Depression Scale (HADS)
 haematological investigations for renal anaemia
 haematocrit (HCT), 41
 haemoglobin, 41
 red cell count (RCC), 41
 white blood cell count and differential, 41–42
 haemodiafiltration (HDF)
 continuous
 AKI, 127, 127
 HD prescription, 154–155
 intermittent, AKI, 126
 on-line, 155
 haemodialysis (HD), 68, 148–182
 anticoagulation, 165–168, 167
 assessment and monitoring during, 177–178
 AVF for, 168, 168–169, 169
 AVG for, 168, 168–169, 169
 the beginning, 1–11, 3, 5
 challenges related to, 154
 children, 281–282
 described, 281
 home HD, 282
 prescribing dialysis and adequacy, 282
 vascular access, 282
 complications during, 179, 180–6
 air embolism, 178–179, 179
 DDS, 178, 179
 diabetes mellitus, 180–181
 haemolysis, 178, 179
 monitoring for, 180
 VND, 179, 179–180
 components for, 149–150, 150
 continuous AKI, 126
 convection, 152, 152
 CVCs for, 169, 169
 defined, 148
 described, 148
 diabetes and management of, 180–181
 dialysate use, 157, 157–158

- dialyser development, 4
- dialysers, 149, 149–150, 150, 158
- diffusion, 151–152, 152
- emotional well-being, 86–90
- extracorporeal circuit, 150, 150
- fluid removal during, 161, 162
- functions of, 150
- home. *see* home haemodialysis (HD)
- home HD, 4–5, 5
- hospital vs. home NICE on, 5
- hyperkalaemia and, 301–302
- intermittent, 126
- later developments, 7
- machine, 150–151, 151
- machine, 150–151, 151
- malnutrition related to, 302–304. *see also* malnutrition
- molecule size, 152
- more frequent and longer, HD prescription, 155–156
- mortality related to, 153
- nocturnal, HD prescription, 156
- patient's perspective on, 181–182
- pre-1920s, 1–2, 1–11, 3, 5
- prescription for, 154. *see also* haemodialysis (HD) prescription
- principles of, 151–152, 153
- refilling during, 162–163, 163
- 1920s, 2
- 1930s, 2
- safety measures for, 148
- 1940s and 1950s, 2–3, 3
- UF, 152–153, 153
- vascular access for, 5, 151, 167–171
 - achieving definitive access provision, 170, 171
 - AVF, 168, 168–169, 169
 - AVG, 168–169, 169f
 - cannulation techniques, 172–174, 173–174. *see also* cannulation techniques, AVF and AVG function preservation
 - care of AVF and AVG, 171
 - CVCs, 169, 169
 - history of, 5
 - TCVCs care, 176
 - types of, 168, 168–169, 169
- haemodialysis (HD) clearance, 158–159
 - HD prescription
 - Kt/V, 159–6
 - URR, 159
 - improving, 159–160
- haemodialysis (HD) prescription, 154
 - blood volume monitoring, 165
 - for children, 281–282
 - dialysate, 157, 157–158
 - temperature of, 165
 - dialysers, 158
 - dialysis modality, 154, 154
 - HDF, 154
 - home HD, 154
 - more frequent and longer HD, 155–156
 - nocturnal dialysis, 156
 - fluid loss management, 162–163, 163
 - fluid removal, 161–162, 162
 - challenges related to, 161
 - dry weight assessment, 161–162, 162
 - HD clearance, 158–159. *see also* haemodialysis (HD) clearance, HD prescription
 - nurse's role, maintaining optimal, 161
 - peak and trough effect of, 154, 154
 - UFR management, 163–164
- haemofiltration (HF), continuous AKI, 126, 126
- haemolysis during HD, 178, 179
- haemolysis investigations
 - haptoglobins, 43
 - lactate dehydrogenase (LDH), 43
 - reticulocytes, 43
- haemolytic uraemic syndrome (HUS) atypical, children, 284
 - children, 284
- Harvard Medical School on brainstem death criteria, 230
- HD. *see* haemodialysis (HD)
- HDF. *see* haemodiafiltration (HDF)
- Health and Social Care Act, 330
- Healthcare Quality Improvement Partnership (HQIP), 329
- health inequalities, kidney disease, 73
- health literacy, 77
- Heart of England Foundation NHS Trust, 135
- heparin
 - anticoagulation, 165–168, 167
 - unfractionated vs. LMWH, clotting management in HD, 166–167, 167
 - use, HD and, 167–168
- hepatitis B, 222
- hepatitis C, 222
- herpes simplex virus (HSV) after renal transplantation, 255
- high-fibre foods, hyperkalaemia management, 296
- histocompatibility antigens, 227
- HIV as contraindication to renal transplantation, 222
- HLA. *see* human leukocyte antigen (HLA)
- home dialysis, 74, 90
- home haemodialysis (HD)
 - children, 282
 - HD prescription, 156–157
 - history of, 4–5, 5
 - hospital vs., 5
- home haemodialysis (HHD), 90–91
- Hospital Anxiety and Depression scale (HADS), 68
- HQIP. *see* Healthcare Quality Improvement Partnership (HQIP)
- H4RT trial, 155
- HSV. *see* herpes simplex virus (HSV)
- HTA. *see* Human Tissue Authority (HTA)
- Hull Laboratory, 9
- human immunodeficiency virus (HIV). *see* HIV

human leukocyte antigen (HLA), renal transplantation, 228, 228
 Human Tissue Act, 231, 239
 Human Tissue Authority (HTA), 231
 human-to-human kidney transplant first, 9
 Hume, 9
 HUS. *see* haemolytic uraemic syndrome (HUS)
 hygiene, oral as factor, renal transplantation, 223
 hyperacute rejection, 250
 hyperamylasaemia, 258
 hyperkalaemia
 AKI-related, 122
 dietary management of, 296
 HD and, 301–302
 hyperlipidaemia
 dietary interventions for, 292–293
 NS, 298–299
 hypertension, dietary management of, 292
 hypoalbuminaemia, causes of, 305

I

IBW. *see* ideal body weight (IBW)
 icodextrin solution, PD, 204
 ideal body weight (IBW) calculation of, 318
 IDH. *see* intra-dialytic hypotension (IDH)
 IDWG. *see* inter-dialytic weight gain (IDWG)
 IHDF. *see* intermittent haemodiafiltration (IHDF)
 IHI. *see* Institute for Healthcare Improvement (IHI)
 immediate pre-operative care for renal transplant recipients, 246
 immune system
 components of, 226–229, 228
 ABO blood groups, 227, **227**
 histocompatibility antigens, 227
 HLA system, 227–228, 228
 leukocytes, 226
 lymphocytes, 226–227
 major histocompatibility complex, 227–228, **228**
 WBCs, 226
 donor and recipient matching for renal transplantation, 226–229, 228
 LRD, 240, 240
 immunisation for immunosuppressed children, 280
 immunosuppression, 248–250
 after renal transplantation, children, 280
 impotence, CKD and, 141
 individual symptom management, 83–85, **84**
 induction, 248
 maintenance, 248–252
 antiproliferative agents, 249
 calcineurin inhibitors, 248–249
 corticosteroids, 248–249
 FK506, 248
 NICE on, 247
 regimes, 247
 renal transplantation, 10, 246–247

induction immunosuppression, 247
 infant(s), renal care of, 274–284
 infection(s). *see also* specific types
 after renal transplantation, 254. *see also* specific types
 AKI-related, management of, 124
 control, 253
 PD-related, 209. *see also* peritonitis, PD and
 TCVCs care, 176
 infertility, CKD effects on, 141
 information and emotional support, pre-operative management of
 renal transplant recipients, 246
 inheritance, tissue-type, 240, 240
 Institute for Healthcare Improvement (IHI), 327, 329
 insulin, IP, 203
 inter-dialytic weight gain (IDWG), 158
 management of, 163–164
 intermittent haemodiafiltration (IHDF), AKI, 126
 intermittent haemodialysis, acute AKI, 125–126
 intermittent peritoneal dialysis (IPD), 8
 International Society for Peritoneal Dialysis (ISPD), 331
 Nursing Liaison Committee of, 215
 International Society of Peritoneal Dialysis, 193
 International Society of Renal Nutrition and Metabolism
 (ISNMRD), 303
 interstitial nephritis, acute AKI related to, 119
 intra-abdominal pressure raised, PD, 207–208
 intra-dialytic hypotension (IDH), 161
 intra-dialytic hypotension (IDH), dialysate temperature, 165
 intra-dialytic peritoneal nutrition (IDPN), 308–309
 intraperitoneal amino acid (IPAA) solution, electrolyte
 formulation of, 205
 intraperitoneal (IP) insulin, during PD for diabetes patients, 203
 IPD. *see* intermittent peritoneal dialysis (IPD)
 ischaemia
 cold, deceased donation, 236
 warm, deceased donation, 236
 ISNMRD. *see* International Society of Renal Nutrition and
 Metabolism (ISNMRD)
 ISPD. *see* International Society for Peritoneal Dialysis (ISPD)

J

JBDS-IP. *see* Joint British Diabetes Societies for Inpatient
 Care (JBDS-IP)
 Joint British Diabetes Societies for Inpatient Care (JBDS-IP), 181

K

KDIGO. *see* Kidney Disease Improving Global Outcomes
 (KDIGO)
 “The KDIGO Controversies Conference on Supportive
 Care, CKD,” 264
 KDOQI. *see* Kidney Disease Outcome Quality Initiative
 (KDOQI)
 KHDE. *see* Kidney Health: Delivering Excellence (KHDE)
 kidney care, 52–65

- description of, 52–65
- introduction, 52
- patient and public involvement, measuring impact of, 65
- patient involvement, care, 52–53
- patient-reported experience measures, 53–60
- QI in, 326–332. *see also* quality improvement (QI)
- reflections on case studies, 60–61
- Kidney Care UK, 74, 76
- kidney disease (KD)
 - biochemical blood investigations, 38, **38**
 - conditions causing chronic and advanced, 30
 - COVID-19 and, 71–73
 - health inequalities, 73
 - psychosocial health of individuals, 70
 - recommendations for change people living with, 69–70
- Kidney Disease Improving Global Outcomes (KDIGO), 121, **121**, 292–295, 294, 297, 298
- Kidney Disease Outcome Quality Initiative (KDOQI), 134, 330
- kidney donors
 - deceased, 229–237, 236. *see also* deceased donation
 - living, 237–243, 239, 240
 - potential
 - clinical care of, 234
 - organ-specific contraindications for, 231, 232
- kidney function
 - assessment of, 133
 - GFR and, 132
- Kidney Health: Delivering Excellence (KHDE), 153, 329
- kidney injury, acute, 115–127. *see also* acute kidney injury (AKI)
- kidney management, conservative, 98–99
- kidney patient involvement network (KPIN), 64–65
- Kidney Quality Improvement Partnership (KQuIP)
 - on patient safety, 329
- kidney replacement therapy (KRT)
 - for AKI, 115–116, 124–128, 126–128
 - children, 279–281, 283
 - dietary management during, 288–312.
 - see also* dietary interventions
 - history of, 6
 - increase, use of, 262–263
 - investigations required prior to, 280, 281
 - median age of patients starting, 263
 - NICE quality statements for, 329–330, **330**
 - patients requiring, prevalence of, 262
- kidney research, patient and carer involvement, 62
- Kidney Research UK, 68, 75
- kidney transplantation (KT), 93–94, 220–258
 - age as factor, 222, 223
 - for AKD, 309–311
 - bone disease after, 310
 - for children, 279–281. *see also* children, renal transplantation for
 - complications of, 254
 - acute rejection, 254
 - ATN, 254
 - infections, 254
 - renal dysfunction, 254
 - urological, 254
 - vascular, 254
 - contraindications to, 221–222
 - as cost-effective care, 220
 - CVD following, 309–310
 - deceased donation, 226–237, 236. *see also* deceased donation
 - donation
 - diabetes mellitus after, 310
 - donor and recipient matching, 226–229, 228
 - immune system, 226
 - LRD, 240
 - pretransplant cross-match, 228
 - sensitisation, 228–229
 - UK matching system, 229
 - for ESKD, 220
 - evaluation for, 222–223, 225
 - cardiac disease, 223
 - obesity, 223
 - oral hygiene, 223
 - peptic ulceration, 223
 - PKD, 222
 - respiratory disease, 223
 - urinary tract, 222–223
 - failing, 97–98
 - first human-to-human, 9
 - future directions, 11
 - history of, 9–11
 - the beginning, 9
 - current, 10
 - first successes, 9–10
 - immunosuppression, 10
 - immunosuppression for, 247. *see also* immunosuppression
 - increasing donor organ supply, 243–244, **244**
 - introduction, 220, 221
 - keeping transplants safe, 231, 232
 - long-term post-transplant care, 309
 - national waiting-list figures for, 221, 221
 - post-operative care, 309
 - pretransplant anxieties and fears, 224–226
 - pretransplant preparation, 223–226
 - rejection, 250–252, 251. *see also* renal transplant rejection
 - surgical technique for, 246, 246–247, 247
 - waiting list for, 226
- Kiil dialyser, 4, 5, 5
- Kolff-Brigham dialysis machine, 3, 3
- Kolff-Brigham kidney, 3
- Kolff dialyser, 2–3
- KPIN. *see* Kidney Patient Involvement Network (KPIN)
- KQuIP. *see* Kidney Quality Improvement Partnership (KQuIP)
- Kt/V
 - HD clearance, 158–159
 - measurement of, 159

L

lack of energy, end-of-life care related to, 269

Landsteiner, 227

Lasker cyler machine, 8

lesbian, gay, bisexual, transgender, and queer (LGBTQ+)
communities, 79–80

leukocyte(s), 226

life participation, 81–82, 82

liver injury, acute, 119–120

living donation, 237–243, 239, 240
altruism, 238
assessment and preparation of donors, 240–242
benefits for transplant recipients, 238
buying and selling of organs, 238–239
for children, 279
discharge, 243
donor and recipient matching, 240
emotional support, 243
ethical issues, 238
future for, 240
hydration, 243
immunological aspects, 240, 240
living unrelated donation, 238
nephrectomy, 242–243
NLDKSS, 239
physical well-being, 237
post-operative management, 243
pre-operative care for donor, 241–242
psychological issues, 240
psychological wellbeing, 237–238
transplant rates, 238, 239
wound management, 243

living donor kidney transplant (LDKT), 94–95

Living Donor Kidney Transplant Programme, 240

living donor transplantation for children, 279

living well with kidney disease, 80–81

LMWH. *see* low-molecular weight heparin (LMWH)

low and lower-middle-income countries (LLMICs), 73

low-molecular weight heparin (LMWH)
anticoagulation, 165–168, 167
clotting management, HD vs. unfractionated heparin,
166–167, 167

lymphatic draining during PD, 190

lymphocyte(s), 226–227

M

major histocompatibility complex, 227–228, 228

malignancy as contraindication to renal transplantation, 221

malnutrition
body composition assessment treatment of, 306
body composition changes with, 297–298
dietary management of, 297–298
HD- and PD-related, 302–304

assessing status, 304
causes of, 303–304
detection of, 304
dietary assessment methods, 304
effects of, 303
nutritional status assessment, 304
nutritional assessment of, 297
nutritional determinants related to, 290–292
PD and, 205
PEW, 303
treatment of, 396

Malnutrition Universal Screening Tool (MUST), 303, 307

MAMC. *see* mid-arm muscle circumference (MAMC)

Maxwell technique, 7

MDRD formula. *see* Modification of Diet in Renal Disease (MDRD) formula

medication(s), post-operative care of renal transplant recipients, 253

Mediterranean diet, 293

membrane resistance, 192

Mental Capacity Act, principles underlying, 267

mesothelium, 190, 191

metabolic acidosis, AKI-related, 123

Michael Reese Hospital, 3

micronutrient(s), nutritional requirements for, 291–292

mid-arm muscle circumference (MAMC), 297–298
body composition assessment, 305

Model for Improvement, 329, 329

Modification of Diet in Renal Disease (MDRD) formula, 132, 133

Modification of Diet in Renal Disease (MDRD) study, 289

molecular weight, 192

molecule(s), HD, 152

Mount Sinai Hospital, 3

Muslim Law Council, 232

MUST. *see* Malnutrition Universal Screening Tool (MUST)

mycophenolate mofetil, maintenance, 249

N

National Academy of Sciences, 10

National Confidential Enquiry into Patient Outcome and Death (NCEPOD), 115

National Co-operative Dialysis study, 205

National Health Service (NHS)
on AKI costs, 115
Next Stage Review report of, 326

National Institute for Clinical Excellence on home vs. hospital HD, 5

National Institute for Health and Care Excellence (NICE)
on AKI, 116, 122
clinical audit tools for, 331
guidelines, 138, 139, 142, 143, 231, 289, 292–293, 294, 327–328
on home HD, 156–157
on immunosuppressive therapy for renal transplantation, 247
on patient safety, 329–330, **330**
on RRT, 330, **330**

- National Institutes of Health (NIH) on nutritional health of patient prior to dialysis, 288
 - National Kidney Foundation (NKF)
 - DOQI of, 289
 - KDOQI of, 43
 - National Living Donor Kidney Sharing Scheme (NLDKSS), 239
 - National Organ Retrieval Service (NORS), 244
 - National Register, 234
 - National Renal Data Set, 293
 - National Research Council, 10
 - National Service Framework (NSF) for Renal Services, 132
 - on MDRD formula, 132, 133
 - on patient safety, 328
 - requirements of, 132
 - National Service Framework for Renal Services: Working for Children and Young People, 329
 - nausea and vomiting, end-of-life care related to, 269
 - Naval Hospital, San Francisco, 7
 - negative-pressure monitoring, history of, 5–6
 - nephrectomy
 - bilateral technique, 235–236, 236
 - deceased donation technique, 235–236, 236
 - living donor, 242–243
 - nephritis, acute interstitial, 119
 - nephrotic syndrome (NS)
 - children, 278–279
 - congenital NS, 279
 - nursing care for, 278–279
 - congenital, children, 279
 - described, 298
 - dietary management of, 298, 299
 - management of, 298, 299
 - protein reduction, 298
 - steroid sensitive, 278
 - nephrotic syndrome, clinical features of
 - intravascular clotting, 32
 - muscle wasting, 32
 - nephrotic syndrome, children, 33
 - oedema, 32
 - proteinuria, 32
 - tiredness and lethargy, 32
 - weight loss and malnutrition, 32
 - nephrotoxicity, AKI related to, 120, **120**
 - new-onset diabetes after transplantation (NODAT), 310
 - Next Stage Review report of NHS, 326
 - NHS. *see* National Health Service (NHS)
 - NHS England, 274
 - NHS Improvement, 327
 - NIH. *see* National Institutes of Health (NIH)
 - NKF. *see* National Kidney Foundation (NKF)
 - NLDKSS. *see* National Living Donor Kidney Sharing Scheme (NLDKSS)
 - nocturnal dialysis, HD prescription, 156
 - nocturnal haemodialysis (HD), haemodialysis prescription, 154
 - NODAT. *see* new-onset diabetes after transplantation (NODAT)
 - nondialytic (conservative) care, 262–271
 - importance of, 262
 - introduction, 262
 - number of patients requiring, 262
 - NORS. *see* National Organ Retrieval Service (NORS)
 - NS. *see* nephrotic syndrome (NS)
 - NSF. *see* National Service Framework (NSF)
 - NSF for Children, Young People, and Maternity Services, 329
 - nurse(s)
 - experienced and well-trained with cannulation techniques, AVF and AVG function preservation, 175
 - HD prescription, 161
 - nursing admission procedure, preoperative management of renal transplant recipients, 245
 - nursing care for NS, children, 278–279
 - Nursing Liaison Committee of ISPD, 215
 - nutrition
 - AKD management, 288–311. *see also* dietary interventions
 - AKI management, 123–124
 - intradialytic peritoneal, 308–309
 - introduction, 288
 - malnutrition-related requirements for, 290–292
 - stage 4 CKD, 138
 - nutritional peritoneal dialysis (PD), 308
 - “Nutrition, CKD,” 298
- ## O
- obesity as factor renal transplantation, 223
 - OCPD. *see* optimised cycling peritoneal dialysis (OCPD)
 - on-line haemodiafiltration (HDF), 154–155
 - ONS. *see* Oral Nutritional Support (ONS)
 - optimised cycling peritoneal dialysis (OCPD), 201, 201
 - oral hygiene as factor, renal transplantation, 223
 - Oral Nutritional Support (ONS), body composition
 - assessment, 307
 - organ(s), donor *see* donor organs
 - buying and selling of, 238–239
 - Organ Donation Taskforce, 243–244
 - organ preservation, deceased donation, 236
 - osmosis during PD, 191, 192
 - osmotic ultrafiltration (UF) during PD, 192
- ## P
- pain
 - end-of-life care related to, 269–270
 - shoulder, PD and, 208
 - palliative care, 262–271
 - advance planning, 266–267
 - communication within team, 266

- palliative care (*cont'd*)
- defined, 262–264
 - described, 262–264
 - dialysis decision-making, 266
 - family communication, 265
 - introduction, 262
 - patient communication, 264–265
 - psychological issues, 270
 - recent government and other initiatives, 264
 - social issues, 270
 - spiritual care, 271
- pancreas-kidney transplantation, 257–258, 258
- pancreatic transplantation, 257–258, 258
- parallel dialyser, 4
- parathyroid hormone (PTH), 39
- patient activation, 82–83
- patient advisory group members, 63
- patient communication, palliative care, 264–265
- patient decision aids (PDAs), 142
- patient involvement
- care, 52–53
 - measuring impact of, 65
 - renal nursing care, PREMs, 182
- Patient Outcome Scale, 268
- patient-reported experience measures, 53–60
- Patient Reported Experience Measures (PREMs), 182
- Patient Reported Outcome Measure (PROM), 182
- patient safety, 327–331, **330**
- clinical practice guidelines, 327–328
 - conversation about, 327
 - defined, 327
 - IHI on, 327
 - KQuIP on, 329
 - NICE on, 329–330, **330**
 - NSF on, 329
- PCR. *see* protein catabolic rate (PCR)
- PD. *see* peritoneal dialysis (PD)
- PDAs. *see* patient decision aids (PDAs)
- PDC test. *see* Personal Dialysis Capacity (PDC) test
- PDEPs. *see* predialysis education programmes (PDEPs)
- PDSA cycles. *see* Plan-Do-Study-Act (PDSA) cycles
- peptic ulceration, evaluation for renal transplantation, 223
- peritoneal cavity, 189, 190
- peritoneal dialysis (PD), 91–93, 189–217. *see also* specific types, e.g., continuous ambulatory peritoneal dialysis (CAPD)
- access and exit site care, 194–199, 195–196, **197**
 - acute, AKI, 127
 - adequacy of
 - assessment of, 205–206
 - creatinine as measure of, 205
 - protein nutrition, 205
 - urea as measure of, 205
 - wellbeing, 205
 - automated. *see* automated peritoneal dialysis (APD)
 - blood glucose control, 203
 - blood-stained effluent, 209
 - catheters, 194, 194–195, 195
 - access and exit site care, 194–199, 195–196, **197**
 - immobilisation of, 198
 - insertion techniques, 196–197, 197
 - long-term care of exit site, 198
 - catheters, 194, 194–195, 195
 - children, 281, 282
 - complications of infectious, 209. *see also* peritonitis, PD and constipation, 208
 - continuous ambulatory. *see* continuous ambulatory peritoneal dialysis (CAPD)
 - continuous cycling, 9, 200, 200
 - for diabetes patients, 202
 - drainage problems, 208
 - education and training for patients, 214–217
 - barriers to learning, 215
 - learning environment, 215
 - recommendations for training within renal units, 215–216
 - what to teach, 216–217
 - for ESKD, 189
 - fibrin formation, 208
 - fluid management, 207
 - goals of, 205
 - history of, 6–7
 - APD, 1
 - CAPD, 9
 - catheter, 7–8
 - current, 10
 - home, 7–8
 - home, history of, 7–8
 - infectious complications of, 209. *see also* peritonitis, PD and
 - intermittent, 8
 - introduction, 189
 - IP insulin, 203
 - malnutrition related to, 205, 302–304.
 - see also* malnutrition
 - malpositioned catheter, 208
 - nutritional, 308
 - optimised cycling, 201, 201
 - parts of, 195, 195
 - patient selection for, 202, **202**
 - perioperative care of patient, 197
 - PET, 193–194, **194**
 - physiology of, 189–194, 190–192, 194
 - blood supply, 190
 - components, 189–194, 190–192, 194
 - convection, 192
 - diffusion, 191–192, 192
 - lymphatic draining, 190

- osmosis, 191, 192
- osmotic UF, 192
- peritoneal membrane transport characteristics, 190, 191
- peritoneal permeability measurement, 192–193
- post-operative care of patient, 197–198
- pre-insertion preparation of patient, 195
- pre-operative care of patient, 196–197, 197
- problem solving, 207–209
- protein loss, 207
- psychological preparation of patient, 196
- raised intra-abdominal pressure problems, 207–208
- removal of, 198–199
- shoulder pain during, 208–209
- sodium sieving, 207
- solution formulation, 203
 - bicarbonate/lactate-based solutions, 204
 - glucose-based solutions, 203–204
 - icodextrin solution, 204
 - introduction, 203
 - IPAA solution, 205
- for special needs, 9
- swimming and bathing with, 198
- tidal, 201, 201
- tubing kinks, 208
- types of, 194–195, 195, 199–200f, 199–201, **202**
- Peritoneal Dialysis International, 212
- Peritoneal Equilibrium Test (PET), 193–194, **194**
- peritoneal interstitium, 190, 191
- peritoneal membrane
 - layers of, 190, 191
 - long-term changes to, 206
 - transport characteristics during PD, 190–191, 191
- peritoneal nutrition, intra-dialytic, 308–309
- peritoneal permeability, measurement of, 192–193
- peritoneum
 - anatomy and physiology of, 189–194, 190–192, 194
 - blood supply to, 190
- peritonitis
 - culture-negative, PD and, 212
 - PD and, 209–210, 211
 - causes of, 209–210
 - culture-negative peritonitis, 212
 - diagnosis of, 210–211, 211
 - exit-site and tunnel infection, 213–214
 - fungal peritonitis, 213
 - obtaining effluent specimen, 211–212
 - permeability changes during, 212
 - prevention of, 209
 - relapsing peritonitis, 213
 - sites of, 209
- Personal Dialysis Capacity (PDC) test, 192
- PET. *see* Peritoneal Equilibrium Test (PET)
- Peter Brent Brigham Hospital, 3
- PEW. *see* protein energy wasting (PEW)
- phosphate
 - binders, 294–295
 - metabolism of, 294
 - reduction, dietary, 294–295
- phosphorus
 - foods with high and low content of, 321–322
 - requirements, dialysis patients, 302
- physical wellbeing, living relation donation, 237
- PKD. *see* polycystic kidney disease (PKD)
- Plan-Do-Study-Act (PDSA) cycles, 329
- plasma exchange, therapeutic, 128
- polyarteritis nodosa, 37–38
- polyclonal antibodies, 248
- polycystic kidney disease, 36
 - clinical features and management of care, 36–37
 - pathology, 36, 36–37
- polycystic kidney disease (PKD), evaluation for renal transplantation, 222
- polyoma virus, after renal transplantation, 255
- portable/wearable equilibrium dialysis technique, 8
- post-kidney transplant, 95–97, **97**
- post-renal failure, AKI related to, 121
- potassium, 39
 - acetate, 157
 - dialysis patients, 301–302
 - foods with high, medium, and lower content of, 322
 - hyperkalaemia management, 296
- potassium disorders, stage 4 CKD, 140
- potassium exchange resins, 296
- potassium portions (exchanges), 324–325
- potential kidney donors
 - clinical care of, 234
 - organ-specific contraindications for, 231, 232
- predialysis dietary interventions, current concepts on, 289–292, 290
- predialysis education programmes (PDEPs), 142, 145
- predialysis phase of CKD, education, 141–145
- prednisolone, maintenance, immunosuppression, 249–250
- pre-emptive transplantation for children, 279–280
- Preferred Place of Care document, 266
- pre-renal failure, AKI related to, 118, 118–119
- pretransplant cross-match, donor and recipient matching for renal transplantation, 228
- PROM. *see* Patient Reported Outcome Measure (PROM)
- prophylactic antibiotics, prior to PD, 196
- protein(s)
 - loss, PD, 207
 - nutrition, PD adequacy assessment, 205
 - reduction of, 298
 - requirements for
 - dialysis patients, 299, 300
 - nutritional, 290–292
- protein catabolic rate (PCR), 305

protein energy wasting (PEW), 303
 body composition assessment, 306
 pruritus, end-of-life care related to, 270
 psychological issues
 LRD, 240
 palliative care, 270
 psychological wellbeing, living relation donation,
 237–238
 PTH. *see* parathyroid hormone (PTH)
 Public Health Service Hospital, 10
 pyelonephritis, 35

Q

QI. *see* quality improvement (QI)
 quality healthcare, components of, 326
 quality improvement (QI)
 defined, 326
 education for people with CKD, 64
 information booklet for patients, 64
 introduction, 326
 kidney care, 326–332. *see also* patient safety
 best practice guidelines for, 330, **330**
 introduction, 326
 methods, 329
 patient safety, 327–331, **328**, 329, **330**
 patient and carer involvement, 63
 training healthcare professionals, 64

R

radiographic investigations, 171–6
 DEXA scan, 305
 rapamycin, maintenance, immunosuppression, 250
 recurrent disease as contraindication to renal transplantation,
 221–222
 relapsing peritonitis, PD and, 213
 religious beliefs, deceased donation and, 231–232
 renal amyloidosis, 37
 renal anaemia, haematological investigations for, **41**
 coagulation, 42
 full blood count, 41
 Renal Association, 158, 159, 166, 193, 204, 206, 240, 290
 best practice guidelines from, 330, **330**
 e-guide for CKD, 135
 on HD prescription, 158
 on interpreting eGFR results, 133
 renal care. *see also* specific types and children
 of infants, children, and young adults, 274–284
 physiology, childhood impact on, 274–275, 275
 renal disease(s). *see also* specific types and chronic kidney
 disease (CKD)
 adolescents, transition to adult services, 284
 established, 275, **275**

renal disease process
 acid–base control, 26
 aldosterone and the control of body potassium content,
 23–24
 anaemia investigations, 42
 ferritin, 42–43
 haematinics, 42
 red-cell folate, 43
 serum iron, 43
 transferrin saturation rate, 43
 vitamin B₁₂, 43
 base fluctuations, healthy individual
 fall, plasma pH, 28
 rise, plasma pH, 28–29
 bicarbonate buffering system, 26
 biochemical blood investigations, kidney disease, 38, **38**
 biochemical blood tests
 albumin, 40
 bicarbonate, 40
 complement, 40
 creatinine kinase, 40
 glycosylated haemoglobin, 40
 immunoglobulins, 41
 lipids, 40
 measuring glucose, 40
 plasma total protein, 40
 serology, 40
 uric acid, 40
 viral serology, 41
 blood pressure control, 29
 calcitrol, 39
 calcium, 39
 computed axial tomography/ computed tomography
 (CAT/CT) scan, 48
 concentration and dilution of urine, 22
 conditions causing chronic and advanced kidney
 disease, 30
 control of bicarbonate ion concentration by kidney,
 26–28
 creatinine, 38
 description of, 14
 diabetic kidney disease, 33
 erythropoietin production by kidney, 29
 estimated glomerular filtration rate (eGFR), 46
 excretion of drugs and drug metabolites, 22
 further investigations for renal anaemia, 42
 glomerular filtration, 18, 18–20, 19
 estimated glomerular filtration rate (eGFR), 20
 glomerulonephritis, 33–34
 crescentic, 35
 focal segmental, 35
 membranous, 34–35
 mesangial, 35

- mesangiocapillary or membrane-proliferative, 35
- minimal-change, 34
- post-infection, 35
- subtypes of, 34
- haematological investigations for renal anaemia, **41**
 - coagulation, 42
 - full blood count, 41
 - haematocrit (HCT), 41
 - haemoglobin, 41
 - red cell count (RCC), 41
 - white blood cell count and differential, 41–42
- haemolysis investigations
 - haptoglobins, 43
 - lactate dehydrogenase (LDH), 43
 - reticulocytes, 43
- kidney biopsy, 47
- kidney function tests, 46
- mineral and bone disorder tests, 39
- multisystem diseases affecting kidney, 37
 - polyarteritis nodosa, 37–38
 - renal amyloidosis, 37
 - scleroderma or systemic sclerosis, 37
 - systemic lupus erythematosus, 37
- nephrotic syndrome, clinical features of
 - intravascular clotting, 32
 - muscle wasting, 32
 - nephrotic syndrome, children, 33
 - oedema, 32
 - proteinuria, 32
 - tiredness and lethargy, 32
 - weight loss and malnutrition, 32
- nephrotic syndrome or nephrosis, 31, 31
- nuclear magnetic resonance/ magnetic resonance imaging, 48
- parathyroid hormone (PTH), 39
- pathology of nephrotic syndrome, 31–32, 32
- phosphate, 39
- polycystic kidney disease, 36
 - clinical features and management of care, 36–37
 - genetics, 36
 - pathology, 36, 36–37
- potassium, 39
- pyelonephritis, 35
- radiographic investigations, 47
 - bone density scan, 48
 - intravenous urogram, 48
 - plain abdominal X-rays, 47–48
 - retrograde pyelogram, 48
 - skeletal X-rays, 48
- reflux nephropathy, 35–36
- regulation of body fluid volume and osmolality, 22
 - aldosterone, 22, 24
 - antidiuretic hormone (ADH), 22, 23
 - atrial natriuretic peptide, 22–23
 - regulation of calcium, phosphate, and magnesium, 25
- renal artery stenosis, 30–31
- renal Doppler studies, 49
 - renal angiogram, 50
 - renal scans, 49
 - renograms, 49
- renal handling of calcium and phosphate, 25–26
- renin–angiotensin–aldosterone pathway, 23
- secretion, 21–22
- selective reabsorption, 20
 - bulk-phase reabsorption, 21
 - fine-tuning reabsorption, 21
 - mechanisms of reabsorption, 20, 21
 - reabsorption, proximal convoluted tubul, 21
- sodium, 38–39
- structure and functions of kidney, 14, 15
 - nephron, 15, 15, 16
 - urinary concentration, 17
 - urinary content, 17–18
 - urinary volume, 15–17, **17**
 - versatility of urine, 15
- ultrasound, 48, 49
- urea, 38
- urine investigations, 43–45, **44**
- renal Doppler studies, 49
 - renal angiogram, 50
 - renal scans, 49
 - renograms, 49
- renal failure
 - AKI related to, **117**, 119–121
 - prerenal, AKI related to, 118, 118–119
- renal function, degree of, 289
- renal nutrition, 288–311. *see also* dietary interventions
- Renal Nutrition Group of BDA, 289
- Renal Registry, 136, 153, 162, 263, 277
- renal transplant recipients
 - complications, 254–8
 - dietary advice for, 310–311
 - discharge from hospital, 255–256
 - immediate preoperative care, 246
 - information and emotional support, 246
 - medical assessment, 245
 - nursing admission procedure, 245
 - ongoing care for, 256–257
 - post-operative care for, 252–254
 - aims of care, 252
 - cardiorespiratory status, 252
 - continuing care, 253–254
 - hydration, 252–253
 - immediate, 252
 - infection control, 253

renal transplant recipients (*cont'd*)

- medications, 253
- pain management, 252
- urine output, 253
- wound management, 253

pre-operative dialysis, 245

pre-operative management of, 244–246

transplant call, 244–245

renal transplant rejection, 250–252, 251

- ABMR, 250, 251
- acute rejection, 251, 251–253, 254
- CAI, 252
- hyperacute rejection, 250, 251
- transplant biopsy, 252
- types of, 250–252, 251

respiratory disease, evaluation for renal transplantation, 223

restless legs syndrome, end-of-life care related to, 270

rhabdomyolysis, AKI related to, 119

RIFLE, 121, **121**

Romans, dialysis history, 1–2

rope ladder technique, AVF and AVG function preservation, 173–174, 174

Royal Free Hospital, 4

S

safety, patient-related, 327–331, **328**, 329, **330**. *see also* patient safety

scleroderma or systemic sclerosis, 37

sclerosis(es), encapsulating peritoneal, 207

selective reabsorption, 20

- bulk-phase reabsorption, 21
- fine-tuning reabsorption, 21
- mechanisms of reabsorption, 20, 21
- reabsorption, proximal convoluted tubul, 21

self-management of stage 3a–3b CKD, 136

sensitization, donor and recipient matching for renal transplantation, 228–229

sepsis, AKI-related, 124

serum bicarbonate, stage 4 CKD, 138

Servelle, 9

Seven-Point Subjective Global Assessment, 319

sexual function, stage 4 CKD effects on, 141

sexuality, 101–103, **102**

SGA. *see* Subjective Global Assessment (SGA)

sharp(s), Health and Safety Executive (Sharps Instruments in Healthcare) Regulations on, 148

shoulder pain, PD and, 208–209

simultaneous pancreas-kidney (SPK) transplant, 257–258, 258

single-needle vs. double-needle dialysis, improving HD clearance, 160–161

sirolimus, maintenance, 250

sleep disturbance, end-of-life care related to, 270

social deprivation, 73–75

social issues, palliative care, 270

socioeconomic deprivation, 74

sodium

- HD prescription, 157, 157–158
- requirements, dialysis patients, 300, 301

sodium sieving, PD, 207

solution formulation for PD, 203. *see also* peritoneal dialysis (PD), solution formulation

SPA. *see* standardised peritoneal assessment (SPA)

Specialist Nurse for Organ Donation (SNOD), 231, 232, 234

special needs, PD for, 7

spiritual care, 271

spirituality, end-of-life care, 271

SPK transplant. *see* simultaneous pancreas-kidney (SPK) transplant

stable housing, 76

standardised peritoneal assessment (SPA), 192

Staphylococcus aureus, 196

steroid sensitive nephrotic syndrome (SSNS), 278

strengths-based approach, 85–86, **85–86**

Subjective Global Assessment (SGA), 298

- body composition assessment, 305–306
- Seven-Point, 319

success, defined, 329

Swan-neck catheter, PD, 195, 195

systemic lupus erythematosus, 37

T

tacrolimus (FK506), 248

T-cell depleting antibodies (TDA), immunosuppression induction, 248

TCVCs. *see* tunnelled central venous catheters (TCVCs) care

TDA. *see* T-cell depleting antibodies (TDA)

team communication, palliative care, 266

telehealth, 72

telemedicine, 71

Tenckhoff catheter, 8

- PD, 194, 195

therapeutic plasma exchange (TPE), AKI, 128

thrombocytopenia, heparin-induced HD and, 167–168

thrombosis, of renal artery or vein, 254

tidal peritoneal dialysis (TPD), 201, 201

tissue-type inheritance, 240, 240

Toronto Western Hospital, 8

TPD. *see* tidal peritoneal dialysis (TPD)

TPE. *see* therapeutic plasma exchange (TPE)

transplant

- biopsy, 252
- call, 244–245
- patients. *see* renal transplant recipients

transplant antigen, 226
 transplantation
 living donor for children, 279
 pancreas-kidney, 257–258, 258
 pancreatic, 257–258, 258
 pre-emptive for children, 279–280
 waiting list, 226
 transplant renal artery stenosis, after renal transplantation, 254
 tubing kinks, PD, 208
 tunnel infection, PD and, 213–214
 tunnelled central venous catheters (TCVCs) care, 169, 169, 176
 flow problems prevention, 216
 infection prevention, 176

U

UF. *see* ultrafiltration (UF)
 UFR. *see* ultrafiltration rate (UFR)
 UK Code of Practice, 230
 UK Donation Ethics Committee, 237
 UK Kidney Association (UKKA), 68, 86, 88, 103, 291–295, 298, 301, 302, 304, 305
 UK matching system, donor and recipient matching for renal transplantation, 229
 UKPDS. *see* UK Prospective Diabetes Study (UKPDS)
 UK Prospective Diabetes Study (UKPDS), 293
 UK Renal Registry. *see* Renal Registry
 ulcer(s), peptic, 223
 ultrafiltration (UF)
 HD, 152–153, 153
 osmotic during PD, 192
 ultrafiltration rate (UFR) management of, 163–164
 ultra-pure water, HD prescription, 157, 158
 ultrasound (US), AKI detection, 122–123
 undergraduate teaching, 61–62
 unfractionated heparin
 anticoagulation, 165–168, 167
 clotting management, HD vs. LMWH, 166–167, 167
 University of Colorado, 10
 University of Hertfordshire, 60
 University of Minnesota, 9
 University of Washington Hospital, 4, 7, 8
 uraemia, AKI-related management of, 123
 urea
 PD adequacy assessment, 205
 rebound, 159
 urea reduction ratio (URR)
 HD clearance, 159
 measurement of, 159
 urinalysis, AKI detection, 122
 urinary tract, evaluation for renal transplantation, 222–223
 urine investigations, 43–44, 44

albumin, 45
 blood, 44
 casts, 45
 causes of proteinuria, 45
 dipstick tests, 44
 glucose, 44
 microalbuminuria, 45
 myoglobin levels, 45
 osmolality, 44
 protein, 44–45
 urinalysis, 44
 urine appearance, 44
 urine microscopy and culture, 45

urine output
 post-operative care of renal transplant recipients, 253
 types of, 125
 urological obstruction, AKI-related, 122
 URR. *see* urea reduction ratio (URR)
 US. *see* ultrasound (US)

V

varicella zoster virus (VZV) after renal transplantation, 255
 vascular access
 children, 282
 for HD, 151, 168–171. *see also* haemodialysis (HD), vascular access for types of, 151–152
 vascular access recirculation, improving HD clearance, 160
 venous needle dislodgement (VND)
 during HD, 179, 179–180
 very low-protein diet (VLPD), 288
 viral infections, after renal transplantation, 254
 vitamin(s)
 for ERF patients, 303
 requirements for
 dialysis patients, 300, 302, 303
 nutritional, 291–292
 vitamin D, metabolism of, 294
 VLPD. *see* very low-protein diet (VLPD)
 VND. *see* venous needle dislodgement (VND)
 volume disorders, stage 4 CKD, 140
 volume overload, AKI-related, 124
 vomiting, end-of-life care related to, 269
 VZV. *see* varicella zoster virus (VZV)

W

waiting list for renal transplantation, 226
 warm ischaemia, deceased donation, 236
 water, ultra-pure, 157, 158
 wellbeing
 PD adequacy assessment, 205
 physical, 237
 psychological, 237–238
 white blood cell(s) (WBCs), 226

WHO. *see* World Health Organisation (WHO)

World Health Organisation (WHO)

“analgesic ladder” of, 269

on palliative care, 263, 264

on phlebotomy, 148

World Kidney Day 2018, 141

wound management, post-operative care of renal transplant recipients, 253

Y

young adults, renal care of, 274–284

Y-system (flush before fill), 8–9

WILEY END USER LICENSE AGREEMENT

Go to www.wiley.com/go/eula to access Wiley's ebook EULA.