

LAW, PALLIATIVE CARE AND DYING

LEGAL AND ETHICAL CHALLENGES

John Lombard



Law, Palliative Care and Dying

Law, Palliative Care and Dying critically examines the role of the legal framework in shaping the boundaries of palliative care practice. The work underlines the importance of a distinct legal framework for specialist palliative care which can provide clarity for both the healthcare professional and the patient. It examines the legal and ethical justifications for specialist palliative care practices and, in doing so, it questions the legitimacy of the distinction between euthanasia and practices such as palliative sedation. Moreover, this work discusses the influence of a human rights discourse on palliative care and examines the contribution of autonomy, dignity, and the right to palliative care.

This book includes detailed comparative research on several European jurisdictions. The jurisdictions illustrate varied approaches to palliative care regulation and promotion. In this manner, the role of professional guidelines and legislation are drawn out and common themes in the regulation of palliative care emerge.

John Lombard is a lecturer in the School of Law, University of Limerick. He teaches Medical Law at undergraduate and postgraduate levels.

This page intentionally left blank

Law, Palliative Care and Dying

Legal and Ethical Challenges

John Lombard

First published 2018
by Routledge
2 Park Square, Milton Park, Abingdon, Oxon OX14 4RN

and by Routledge
711 Third Avenue, New York, NY 10017

Routledge is an imprint of the Taylor & Francis Group, an informa business

© 2018 John Lombard

The right of John Lombard to be identified as author of this work has been asserted by him in accordance with sections 77 and 78 of the Copyright, Designs and Patents Act 1988.

All rights reserved. No part of this book may be reprinted or reproduced or utilised in any form or by any electronic, mechanical, or other means, now known or hereafter invented, including photocopying and recording, or in any information storage or retrieval system, without permission in writing from the publishers.

Trademark notice: Product or corporate names may be trademarks or registered trademarks, and are used only for identification and explanation without intent to infringe.

British Library Cataloguing in Publication Data

A catalogue record for this book is available from the British Library

Library of Congress Cataloging in Publication Data

Names: Lombard, John, (Law teacher), author.

Title: Law, palliative care and dying : legal and ethical challenges /
John Lombard.

Description: New York, NY : Routledge, 2018. | Includes bibliographical references and index.

Identifiers: LCCN 2017060234 | ISBN 9781138744646 (hbk) |
ISBN 9781351716734 (web pdf) | ISBN 9781351716727 (epub) |
ISBN 9781351716710 (mobipocket)

Subjects: LCSH: Terminal care—Law and legislation—Europe. | Palliative treatment—Europe. | Euthanasia—Law and legislation—Europe.

Classification: LCC KJC6229.E95 L66 2018 | DDC 344.404/197—dc23

LC record available at <https://lccn.loc.gov/2017060234>

ISBN: 978-1-138-74464-6 (hbk)

ISBN: 978-1-315-17956-8 (ebk)

Typeset in Galliard
by Taylor & Francis Books

Contents

<i>Acknowledgements</i>	ix
<i>Table of Legislation</i>	x
<i>Table of Cases</i>	xv
Introduction: law, palliative care and dying: legal and ethical challenges	1
<i>Introduction to central themes</i>	3
<i>Terminology</i>	4
Palliative care	4
Specialist palliative care	6
End-of-life care	7
Euthanasia	7
<i>Defining the research boundaries</i>	9
<i>Chapter structure</i>	11
1 The development and practice of palliative care	15
1.0 Introduction	15
1.1 The development of hospice and palliative care	16
1.1.1 The emergence of modern palliative care	19
1.1.2 Expansion in categories of palliative care patients	23
1.2 Palliative care providers	25
1.2.1 Hospice care	25
1.2.2 Hospitals	26
1.2.3 The community setting	28
1.3 Palliative care practices	32
1.3.1 Sedation in palliative care	33
1.3.2 Artificial nutrition and hydration	44
1.4 Conclusion	46

2	Specialist palliative care and euthanasia: a legitimate distinction?	48
	2.0 <i>Introduction</i>	48
	2.1 <i>Euthanasia: law and practice in the Netherlands</i>	49
	Defining ‘lasting and unbearable suffering’	51
	2.2 <i>Murder: identifying the requisite intention</i>	54
	2.3 <i>The legal and ethical justification of specialist palliative care practices</i>	57
	2.3.1 The doctrine of double effect	57
	2.3.2 Palliative sedation without artificial nutrition and hydration	70
	2.4 <i>Conclusion</i>	79
3	The human rights framework for palliative care	81
	3.0 <i>Introduction</i>	81
	3.1 <i>Defining the concept of autonomy</i>	82
	3.1.1 The role of autonomy in advancing palliative care goals	83
	3.1.2 The liberal conception of autonomy in palliative care	84
	3.1.3 Patient autonomy and the law	87
	3.1.4 The refusal of medical treatment	89
	3.1.5 A demand for medical treatment	91
	3.1.6 Capacity in Ireland and England and Wales	94
	3.2 <i>The concept of dignity in palliative care</i>	98
	3.2.1 Inadequate palliative care provision as inhuman or degrading treatment?	101
	3.2.2 The right to physical integrity – respect for private and family life	106
	3.3 <i>A right to palliative care?</i>	109
	3.3.1 Advocating for a right to palliative care	110
	3.3.2 The basis of a right to palliative care in international law	112
	3.3.4 The basis of a right to palliative care in domestic law	115
	3.4 <i>Conclusion</i>	117
4	The legal framework for palliative care in the United Kingdom and Ireland	119
	4.0 <i>Introduction</i>	119
	4.1 <i>The legal framework in England and Wales for palliative care</i>	120
	4.1.1 Shaping palliative care provision and development	120
	4.1.2 The standard setting function of the General Medical Council	126
	4.1.3 The demise of the Liverpool Care Pathway	128

4.1.4	The planning and commissioning of palliative care services	130
4.1.5	The contribution of the National Institute for Health and Care Excellence	131
4.1.6	An emerging legislative response to palliative care provision	133
4.2	<i>The legal framework for palliative care in Ireland</i>	138
4.2.1	A framework for palliative care development	139
4.2.2	The Irish Medical Council	140
4.2.3	The Nursing and Midwifery Board of Ireland	142
4.2.4	Diverging standards and practice	145
4.2.5	The Irish Association of Palliative Care	146
4.3	<i>The European Association of Palliative Care</i>	149
4.3.1	EAPC recommended framework for the use of sedation in palliative care	150
4.4	<i>Palliative care as a legal process</i>	152
4.5	<i>Conclusion</i>	153
5	The legal framework for palliative care in the Netherlands	154
5.0	<i>Introduction</i>	154
5.1	<i>The development of palliative care in the Netherlands</i>	155
5.2	<i>Guidelines on specialist palliative care in the Netherlands</i>	158
5.3	<i>The KNMG Guideline for Palliative Sedation</i>	160
5.3.1	Defining the practice of palliative sedation	161
5.3.2	Indications and preconditions for palliative sedation	161
5.3.3	The decision-making process for palliative sedation	165
5.3.4	The administration of fluids in palliative care	171
5.3.5	The administration of palliative sedation	173
5.3.6	The impact of the KNMG Guideline for Palliative Sedation	174
5.3.7	Normal medical practice: a sufficient justification?	178
5.4	<i>Conclusion</i>	180
6	The legal framework for palliative care in France	182
6.0	<i>Introduction</i>	182
6.1	<i>End-of-life care: an evolving social and legal paradigm</i>	183
6.1.1	The conflict of autonomy and medical paternalism	187
6.2	<i>The legal framework for palliative care</i>	188
6.3	<i>Law n° 99-477 of 9 June 1999</i>	188
6.4	<i>Law n° 2002-303 of 4 March 2002</i>	189
6.5	<i>Law n° 2005-370 of 22 April 2005</i>	191

6.5.1 The withholding and withdrawal of medical treatment	192
6.5.2 Recognition of patient autonomy	193
6.5.3 Double effect reasoning	195
6.5.4 Developing palliative care capacity	196
6.6 <i>Decision-making in practice: pre- and post-Leonetti</i>	196
6.7 <i>Law n° 2016-87 of 2 February 2016</i>	198
6.7.1 Penser solidairement la fin de vie	199
6.7.2 Substance of the Claeys-Leonetti Law	200
6.7.3 Defining the practice of continuous deep sedation: a practice beyond palliative medicine?	202
6.7.4 Indications and preconditions for continuous deep sedation	203
6.7.5 The decision-making process for continuous deep sedation	206
6.7.6 The administration of artificial nutrition and hydration	208
6.7.7 The administration of continuous deep sedation	209
6.7.8 Converging practices at the end-of-life?	210
6.7.9 The impact of the Claeys-Leonetti law	212
6.8 <i>Conclusion</i>	213
Conclusion: law, palliative care and dying	215
<i>The legitimacy of the distinction between specialist palliative care practices and euthanasia</i>	215
<i>The human rights framework for palliative care</i>	217
<i>A contemporary ars moriendi in law</i>	219
<i>Conclusion: the way forward</i>	222
 <i>Bibliography</i>	 223
<i>Index</i>	254

Acknowledgements

To all my teachers, mentors, family, friends and colleagues.

To Mom, Dad, Eileen, and Lydia.

I thank you.

Table of Legislation

Belgium

The Belgian Act on Euthanasia of May, 8th 2002 49

England and Wales

Abortion Act 1967 10

Access to Palliative Care Bill 2015 124, 131, 134, 135–7, 220

 s 2(1). 135

 s 2(2). 136

 s 3. 136

 s 3(1)(a). 136

 s 3(1)(c). 136

Access to Palliative Care Bill 2017 131, 134, 137–8, 220

 s 2(2). 138

Assisted Dying for the Terminally Ill Bill 2005. 133

 s 2(2). 133

Medical Act 1983

 s 1B. 126

Mental Capacity Act 2005 94, 96, 122, 124, 125, 127, 136, 219

 s 1. 94

 s 1(3). 94

 s 2. 94

 s 2(2). 94

 s 3(1). 94

 s 4. 95

 s 4(2). 95

 s 4(6). 95

 s 4(6)(a). 96

 s 4(7). 96

 s 25. 96

 s 25(5). 97

 s 26(1). 96–7

Palliative Care Bill 2006	134
s 1(1).	134
Palliative Care Bill 2008	134–5
s 1(1).	134–5

Council of Europe

European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Strasbourg, 26.XI.1987 Text amended according to the provisions of Protocols No. 1 (ETS No. 151) and No. 2 (ETS No. 152), which entered into force on 1 March 2002	101
European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (European Convention on Human Rights, as amended) (ECHR).	117, 219
Art 2	91, 92
Art 3	91, 92, 101, 102, 103, 104, 105, 106, 109, 218
Art 8	87, 91, 92, 106, 107, 108, 109
Art 8(2).	106, 108
Art 9	91
Art 14	91
Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003	16, 17, 48, 111

European Union

Charter of Fundamental Rights of the European Union [2010] OJ C83/380	106
Art 4	101
Art 7	88

France

Loi n° 91-748 du 31 juillet 1991 portant réforme hospitalière	186, 188, 221
Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs	183, 188–9, 196, 199
Art L. 1er A	188
Art L. 1er B	188
Art L. 1er C	189
Art 10	189
Art 11	189
Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé	183, 188, 189–90, 196, 199, 200
Art 3	190
Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie	183, 188, 191–6, 197, 198, 199–200, 210, 213, 221

xii *Table of Legislation*

Art 1	192
Art 2	195
Art 4	194
Art 5	192
Art 6	193
Art 9	192–3
Art 11	196
Art 12	196
Art 13	196
Art 14	196
Art 15	196
Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie	126, 183, 188, 198–214, 221
Art 1	203
Art 2	208
Art 3	202, 203, 207, 208
Texte n° 301 (1977-1978) relative au droit de vivre sa mort présentée par M. Henri Caillavet	184

Ireland

Assisted Decision-Making (Capacity) Act 2015	94, 97, 220
Pt 8	97
s 3	95
s 3(3)	95
s 8	96
s 8(2)	94
s 8(6)	96
s 8(7)	96
s 8(8)	96
s 84	97
s 84(2)	97
s 84(3)	97
s 85(3)	97
s 85(4)	97
Criminal Justice Act 1964	
s 4	55
s 4(2)	56
Criminal Justice Act 1967	
s 8	56
Criminal Law (Suicide) Act 1993	
s 2(2)	138
Equal Status Act 2000	143
Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009	

s 14(1)	138
Irish Medicines Board (Miscellaneous Provisions) Act 2006	144
Medical Practitioners Act 1978	140
Medical Practitioners Act 2007	140
s 6	140
s 7(2)(i)	140
Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations 2007, S.I. 201 of 2007	144
Misuse of Drugs (Amendment) Regulations 2007, S.I. 200 of 2007	145
Nurses Act 1950	142
Nurses Act 1985	142
Nurses and Midwives Act 2011	
s 8	142
Protection of Life During Pregnancy Act 2013	10

Luxembourg

Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide	49
---	----

Netherlands

Dutch Penal Code	52
Art 293	50
Art 293(1)	50
Art 293(2)	50, 51
Art 294	50
Art 294(2)	50
Medical Treatment Contracts Act 1994	169
Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001	50, 51, 53, 168, 181
Art 2	50, 167
Art 2(1)	54

New York

Palliative Care Access Act 2011	126
Palliative Care Information Act 2011	126, 218

United Nations

Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984	101
Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo 4.IV.1997	106

Convention on Psychotropic Substances 1971 114

International Covenant on Civil and Political Rights 1966

 Art 7 101

International Covenant on Economic, Social and Cultural Rights 1966

 115, 116, 117

 Art 2(1) 112

 Art 12 112

 General Comment No 14 113

Single Convention on Narcotic Drugs 1961 105, 114

Universal Declaration of Human Rights 1949 101, 143

 Art 25 112

Table of Cases

<i>A, B, and C v Ireland</i> [2010] ECHR 2032	108–9
<i>Airedale N.H.S. v Bland</i> [1993] AC 789	69, 75–6, 90, 216
<i>An NHS v D</i> [2012] EWHC 885 (COP)	97
<i>An NHS Trust v H</i> [2001] 2 FLR 501	76
<i>An NHS Trust v M</i> [2001] 2 FLR 367	76
<i>Barnett v Chelsea and Kensington Hospital Management Committee</i> [1969] 1 QB 428	75
<i>BB v France</i> , App no 30930/96 (ECtHR, 7 September 1998)	103
<i>Bensaid v United Kingdom</i> (2001) ECHR 82	102
<i>Burke, R (on the application of) v The General Medical Council</i> [2004] EWHC 1879 (Admin).	82
<i>Carter v Canada (Attorney General)</i> 2012 BCSC 886	50
<i>Compassion in Dying v Washington</i> 79 F. 3d 790, 1996 US App Lexis 3944	67
<i>Cruzan v Director Missouri Department of Health</i> 497 US 261 (1990)	77
<i>D v United Kingdom</i> (1997) 24 EHRR 423	102–3, 218
<i>Fitzpatrick and Another v K and Another</i> [2008] IEHC 104	94, 95
<i>Fleming v Ireland & Ors</i> [2013] IEHC 2, [2013] IESC 19	44, 61, 70–1, 138
<i>Frenchay Healthcare NHS Trust v S</i> [1994] 2 All ER 403	76
<i>Garnier</i> , Conseil d’État, 29 July 1994	187
<i>Governor of X Prison v McD</i> [2015] IEHC 259	97
<i>Glass v United Kingdom</i> (2004) 39 EHRR 15	106–7
<i>HE v A Hospital Trust</i> [2003] EWHC 1017	96
<i>Heeney v Dublin Corporation</i> [1998] IESC 23	115–16
<i>Herczegfalvy v Austria</i> (1992) 15 EHRR 437	102, 103, 104
<i>Hoge Raad (Supreme Court of the Netherlands)</i> , 24 December 2002, NJ 2003, 167	50, 53
<i>Hoge Raad (Supreme Court of the Netherlands)</i> , 21 June 1994, NJ 1994, 656	50, 52
<i>Hoge Raad (Supreme Court of the Netherlands)</i> , 27 November 1984, NJ 1985, No. 106	50
<i>In the Matter of Art 26 of the Constitution and the Health (Amendment) (No 2) Bill 2004</i> [2005] IESC 7	116

<i>Ireland v United Kingdom</i> [1978] ECHR 1	101, 103
<i>Keenan v United Kingdom</i> (2001) 33 EHRR 913	102, 103, 104
<i>Kudla v Poland</i> (2000) 35 EHRR 198	103–4
<i>L v Lithuania</i> (2008) 46 EHRR 22	103
<i>Lambert and Others v France</i> App 46043/14, (ECtHR, 25 June 2015)	208
<i>Mouisel v France</i> , App No 67263/01 (14 November 2002), (2004) 38 EHRR 34	102
<i>Nederlandse Jurisprudentie</i> 1973, no. 183, District Court of Leeuwarden, 21, February 21, 1973	49
<i>Nevmerzhitsky v Ukraine</i> (2006) 43 EHRR 32	104
<i>Pretty v United Kingdom</i> (2002) 35 EHRR 1	82, 91, 101, 102, 106
<i>Price v the United Kingdom</i> , App no 33394/96, (ECtHR, 10 July 2001)	102
<i>The People (DPP) v Douglas and Hayes</i> [1985] ILRM 25	56
<i>The People (DPP) v Murray</i> [1977] IR 360	55–6
<i>R v Adams</i> [1957] Crim LR 773	67–8
<i>R v Central Birmingham Health Authority, ex parte Walker</i> (1987) 3 BMLR 32	116
<i>R v Cox</i> (1992) 12 BMLR 38	68
<i>R v Gibbins and Proctor</i> (1918) 13 Cr App Rep 134	74
<i>R v Secretary of State for Social Services ex parte Hincks</i> (1979) 123 Sol Jo 436	116
<i>R v Stone and Dobinson</i> [1977] QB 354	74
<i>R v Woolin</i> [1998] 4 All ER 103	55
<i>Raninen v Finland</i> , App no 20972/92 (16 December 1997)	102
<i>R(Burke) v General Medical Council</i> [2006] QB 273, [2005] EWCA Civ 1003	91–3
<i>R(Nicklinson) v Ministry of Justice</i> [2013] EWCA Civ 961, [2013] HRLR 36	69
<i>R(Rose) v Thanet Clinical Commissioning Group</i> [2014] EWHC 1182 (Admin).	132
<i>Re C (Adult: refusal of treatment)</i> [1994] 1 All ER 819	94
<i>Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)</i> [2011] EWHC 2443 (Fam), [2012] 1 WLR 1653	76
<i>Re T (Adult: Refusal of Medical Treatment)</i> [1992] 3 WLR 782, [1992] EWCA Civ 18	87
Report of November 5, 1969, Yearbook of the European Convention on Human Rights, Vol. XII (1969)	102
<i>Rodriguez v British Columbia</i> [1993] 3 SCR 519	66–7
<i>Ryan v Attorney General</i> [1965] IR 294	106
<i>Selmouni v France</i> (2000) 29 EHRR 403	104
<i>Senanyake</i> , Cour administrative d’appel de Paris, 9 June 1998	187
<i>State (C) v Frawley</i> [1976] 1 IR 365	101
<i>Swindon and Marlborough NHS Trust v S</i> [1995] 3 Medical Law Review 84	76
<i>Tanko v Finland</i> , App no 23634/94 (Commission Decision, 19 May 1994)	103

<i>Tatete v Switzerland</i> , App no 41874/98 (ECtHR, 6 July 2000)	103
<i>Tysi�c v Poland</i> (2007) 45 EHRR 42	91, 107–8, 109, 218
<i>Vacco v Quill</i> 521 US 793 (1997)	66, 88
<i>Vala�inas v Lithuania</i> , App no 44558/98, (24 July 2001)	102
<i>W Healthcare NHS Trust v KH</i> [2004] EWCA Civ 1324, [2005] 1 WLR 834	76
<i>Ward of Court (withholding medical treatment) (No 2), Re</i> , [1996] 2 IR 79, [1995] 2 ILRM 401	75, 76, 77, 82, 88, 90–1, 97, 138
<i>W(by her litigation friend B) v M(by her litigation friend, the Official Solicitor) and S and A NHS Primary Care Trust</i> [2011] EWHC 2443 (Fam)	76
<i>X v Denmark</i> (1992) 15 EHRR 437	102
<i>Z and Others v the United Kingdom</i> (2002) 34 EHRR 3	101

This page intentionally left blank

Introduction

Law, palliative care and dying: legal and ethical challenges

In 'Aubade' the poet Philip Larkin wrote '[m]ost things may never happen: this one will'.¹ This set out that death is something which cannot be avoided and is a reality which is to be accepted. It is a reality which is bundled with much philosophical analysis as well as religious and social mores.² Our understanding of death and the ability to treat pain experienced by the patient at the end of life has developed in line with advancements in science and technology. Technology now has a substantial impact on the way people both live and die. This leads to a degree of friction between the treatment of the patient and the philosophical, religious, and social mores associated with death and dying. Hanafin suggested that, as a result of death becoming increasingly medicalised, this signals the first move towards 'the need for legal intervention in this area'.³ In this regard, end-of-life care raises important legal and ethical issues about the treatment and care available to patients. End-of-life care may take a variety of forms and its precise content is often influenced by jurisdiction. While reference will be made to practices such as euthanasia, this work concentrates on palliative and specialist palliative care practices and the emerging legal framework in several European jurisdictions in respect of palliative practices.

Specialist palliative care is a form of palliative care which is normally provided to patients who are expected to die within a short period of time. The practice of palliative care has an increasingly important role in healthcare systems across Europe as it is being provided to a growing number of patients near the end of

1 P. Larkin, 'Aubade' in H. Pinter, G. Godbert and A. Astbury (eds), *100 Poems by 100 Poets* (Methuen 1986) 93.

2 P. Ariès, *Western Attitudes toward Death: From the Middle Ages to the Present* (P. Ranum tr, John Hopkins University Press 1975); P. Ariès, *The Hour of Our Death* (Random House 1991); J.E. Seymour, R. Janssens and B. Broeckaert, 'Relieving suffering at the end of life: Practitioners' perspectives on palliative sedation from three European countries' (2007) 64 *Social Science & Medicine* 1679, 1679 'Questions about how to manage the dying process are now matters of intense clinical and societal debate, alerting us to how death is both a socially organised and profoundly physical transition and related to beliefs and values at an individual, social and societal level.'

3 P. Hanafin, *Last Rights: Death, Dying and the Law in Ireland* (Cork University Press 1997) 7.

2 Introduction

life. This is due to an aging population, an increase in the incidence of cancer,⁴ and incurable chronic health conditions. In the UK, the population was estimated to be 64.6 million in mid-2014 and is expected to increase to 74.3 million by 2039.⁵ This population projection suggests that there will be an 89.3% increase in the number of people aged 75 and over in the UK by mid-2039.⁶ Similar increases have also been forecast for the European Union⁷ and across the globe.⁸ The older population accounts for many cancer diagnoses but they also experience diseases such as chronic obstructive pulmonary disease;⁹ diseases which are marked by a slow-progression rather than a rapid decline. In the coming years, there will therefore be greater pressure on healthcare systems across Europe to provide high quality palliative care for such patients. Addressing this challenge requires recognition of the many perspectives from which this issue can be approached.

Ensuring appropriate palliative care is available in a country is a public health issue and encompasses cultural, clinical, legal, and ethical dimensions. There are often over-lapping concerns, many of which will emerge in this work. The central theme of this work is the importance and role of an appropriate legal framework to guide specialist palliative care practices. The legal framework has an essential role in demarcating the bounds of palliative care provision through reference to human rights, normative concepts, and ethical justifications which frame the legitimacy of clinical practice. However, the legal framework for specialist palliative care is of broader significance and it has been used in some jurisdictions to shape debates about what constitutes appropriate end-of-life care. This point will be drawn out

4 Cancer Research UK, 'Cancer Incidence Statistics' <<http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence#heading-Zero>> accessed 20 February 2017 'Incidence rates for all cancers combined are projected to rise by 2% in UK between 2014 and 2035, to 742 cases per 100,000 people by 2035.'

5 Office for National Statistics, 'National Population Projections: 2014-based Statistical Bulletin' (ONS 2015) 2.

6 Ibid., 8.

7 Eurostat, 'People in the EU: who are we and how do we live?' (Publications Office of the European Union 2015) 161 'The share of the elderly in the total population of the EU-28 is projected to increase from 18.5 % (or 93.9 million elderly persons) in 2014 to 28.7 % (or 149.1 million elderly persons) by 2080.'; J. Cohen and L. Deliens, 'Applying a public health perspective to end-of-life care' in J. Cohen and L. Deliens (eds) *A Public Health Perspective on End of Life Care* (Oxford University Press 2012) 6.

8 United Nations, Department of Economic and Social Affairs, Population Division, 'World Population Ageing Report 2015' (ST/ESA/SER.A/390) 2 'Between 2015 and 2030, the number of people in the world aged 60 years or over is projected to grow by 56 per cent, from 901 million to 1.4 billion and by 2050, the global population of older persons is projected to more than double its size in 2015, reaching nearly 2.1 billion.'

9 Cancer Research UK, 'Cancer Incidence Statistics' <<http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence#heading-Zero>> accessed 20 February 2017. Between 2012 and 2014 the peak rate of cancer cases was among people aged 85 years and over. Office for National Statistics, 'Cancer Registration Statistics, England: 2014' (ONS 2016) 2 'Cancer is a disease of the elderly, as approximately 12% of the population are aged 70 and above and account for 50.2% of the total cancers registered in 2014.'

through discussion of the legal framework in various jurisdictions. It should be noted that in undertaking such analysis, this work will remain cognisant of the influence and contribution which other disciplines can make to the debate.

Introduction to central themes

The central themes which are addressed in this book are structured in such a manner as to build upon each other and provide a logical progression for this work. They address key issues raised by the provision of specialist palliative care and underline the necessity of examining the emerging legal framework for this form of care.

The first core issue to be examined is the distinction between euthanasia and specialist palliative care practices. This is a necessary step to demonstrate the legality of practices such as palliative sedation and the related but distinct practice of withdrawing artificial nutrition and/or hydration. This will be achieved by examining the interpretation and application of the doctrine of double effect as well as considering the acts and omissions dichotomy. These justifications may be relied on in cases where the actions of a healthcare professional suggest an intention other than providing appropriate palliative care and/or pain management. It will be argued that a legitimate distinction does exist but that, for several reasons, the reliance placed on the doctrine of double effect is no longer appropriate. The doctrine does not provide a sufficiently consistent basis to support these practices and requires a carefully delineated course of sedation if the doctrine is to be satisfied. In addition to this, research on the impact of sedative drugs suggests that, when appropriately administered, there is little evidence that the death of a patient is hastened. Reliance on such justifications therefore serves to further obfuscate the legal, ethical, and clinical status of palliative sedation.

The second core point to be addressed in this monograph is the emerging legal framework for specialist palliative care practices which exists in several European jurisdictions. The focus is on specialist palliative care for adults and not paediatric palliative care. This distinction is made due to the differences between paediatric and adult palliative care as well as the additional challenges raised in providing palliative care to children.¹⁰ This work is predominantly grounded in the UK and Irish legal frameworks but there are also chapters which examine the Dutch regulations on palliative sedation and the French legislation on practices at the end of life. The legal framework in these jurisdictions will begin to highlight differences in the goals and normative conceptions of palliative care which exist across jurisdictions. This point will be drawn out over the course of several chapters. Moreover, discussion of these jurisdictions will illustrate the role which specialist palliative care has in shaping the legal status of euthanasia. This role has proven to be particularly malleable and the congruence between these practices has shifted depending on the overarching objective that a party seeks to achieve.

10 J.L. Hynson and S.M. Sawyer, 'Paediatric palliative care: Distinctive needs and emerging issues' (2001) 37(4) *Journal of Paediatrics and Child Health* 323; J.L. Hynson and others, 'The dying child: how is care different?' (2003) 179 (6 Suppl) *Medical Journal of Australia* S20.

4 Introduction

This book takes account of cultural and social factors which shape the provision of palliative care in each jurisdiction. Consequently, this work refrains from arguing that any specific legal framework is best but it does seek to highlight the influential role which the legal framework can have in shaping the provision of specialist palliative care and broader end-of-life practices. In this respect, a number of points are advanced over the course of the work. It is argued that the legal framework should ensure and maintain a legitimate distinction between specialist palliative care and euthanasia. The framework must effectively protect and promote the human rights of the patient, and it must provide sufficient clarity and certainty to both the patient and the healthcare professional. The manner in which these points are achieved will vary by jurisdiction and may involve a mix of professional regulations, legislation, or legal norms. The basis for these arguments cannot be fully explored in the confines of this introduction but will be developed over the course of this work.

Overall, this monograph aims to bridge the gap between the existing literature which has been approached predominantly from an ethical perspective and literature from a legal background which has not engaged in practical analysis of specialist palliative care or fully considered the role and influence of human rights. Palliative care is a multidisciplinary practice; therefore, research of this area cannot and should not be one-dimensional.

Terminology

The terms ‘palliative care’, ‘specialist palliative care’, ‘end-of-life care’, and ‘euthanasia’ are used throughout this work. It is necessary to define these terms at an early stage to provide clarity in the subsequent use of these terms and to highlight similarities and differences which may go beyond the purely semantic. Defining these terms begins to illustrate the complexity of distinguishing between several of these practices from a legal and ethical perspective. Legal and ethical concerns are closely aligned in specialist palliative care given the condition of the patient and they often serve to complicate discussion.

Palliative care

Cairns stated that ‘[n]o other area of health care seems to have gone to such lengths to write a definition of itself as has palliative care.’¹¹ Multiple definitions have been advanced and subsequently refined over the years.¹² These definitions have evolved in line with clinical developments but also reflect a practice that is attempting to negotiate and characterise its role in the care of the patient. Elements common to many definitions of palliative care include a focus on the quality of life of the patient, the multidisciplinary nature of the practice, and the influence of the

11 W. Cairns, ‘The problem of definitions’ (2001) 9(5) *Progress in Palliative Care* 187, 187.

12 T. Pastrana and others, ‘A matter of definition – key elements identified in a discourse analysis of definitions of palliative care’ (2008) 22 *Palliative Medicine* 222 ‘A total of 37 English and 26 German definitions were identified and analysed.’

patient's family.¹³ These elements are present in the World Health Organization (WHO) definition of palliative care. The WHO define palliative care as:

... 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:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.¹⁴

This definition has been cited extensively in journal articles, reports, and will reflect the understanding of 'palliative care' as it is used in this work.¹⁵

13 Ibid., 229.

14 World Health Organization, 'WHO Definition of Palliative Care' <<http://www.who.int/cancer/palliative/definition/en/>> accessed 4 March 2017; C. Sepúlveda and others, 'Palliative care: the World Health Organization's global perspective' (2002) 24 (2) *Journal of Pain and Symptom Management* 91, 94; European Association of Palliative Care, 'Definition of palliative care' <<http://www.eapcnet.eu/Corporate/AbouttheEAPC/DefinitionandAims.aspx>> accessed 3 March 2017. 'Palliative care is the active, total care of the patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and of social, psychological and spiritual problems is paramount.

Palliative care is interdisciplinary in its approach and encompasses the patient, the family and the community in its scope. In a sense, palliative care is to offer the most basic concept of care – that of providing for the needs of the patient wherever he or she is cared for, either at home or in the hospital.

Palliative care affirms life and regards dying as a normal process; it neither hastens nor postpones death. It sets out to preserve the best possible quality of life until death.'

15 F.E.M. Murtagh, 'Patterns of dying: palliative care for non-malignant disease' (2004) 4(1) *Clinical Medicine* 39; H.M. Chochinov, 'Dying, dignity and new horizons in palliative end-of-life care' (2006) 56(2) *A Cancer Journal for Clinicians* 84; T. Jaarsma and others, 'Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology' (2009) 11(5) *European Journal of Heart Failure* 433; Health Service

6 Introduction

Nevertheless, this definition still leaves many elements to be unpacked such as the meaning of 'quality of life'.¹⁶ Such points have been the subject of considerable debate and illustrate the contested taxonomy and ontology underlying this practice.

The WHO definition of palliative care makes it clear that the provision of palliative care is not to be confined to the end stages of an illness. Instead the 'principles of palliative care should be applied as early as possible in the course of any chronic, ultimately fatal illness'.¹⁷ This expansion in palliative care provision is reflected in the point that palliative care is not a single type of care. Rather, there are different levels of provision. Palliative care can be provided by way of the palliative care approach, general palliative care, or specialist palliative care.

The palliative care approach is the application of the principles of palliative care by all healthcare professionals.¹⁸ This type of care is not limited by location and concentrates largely on the provision of care based on palliative care principles such as focusing on the quality of life.¹⁹ General palliative care is an 'intermediate level' of palliative care.²⁰ This level of care is provided by a healthcare professional who has 'additional training and experience in palliative care'²¹ but does not specialise in palliative care. The third level is specialist palliative care.

Specialist palliative care

It is the pain management and broader practices closely associated with specialist palliative care that raise the legal and ethical difficulties that this work will address. These difficulties include the issue of what constitutes appropriate pain management. This relates to the provision of palliative sedation and the practice of withdrawing artificial nutrition and hydration. Specialist palliative care can be described as being

Executive, 'Palliative Care Services – Five Year/Medium Term Development Framework' (Health Service Executive 2009) 12.

16 Pastrana (note 12) 225; Fiona Randall and R.S. Downie, *The Philosophy of Palliative Care: Critique and Reconstruction* (Oxford University Press 2006).

17 Sepúlveda (note 14) 92.

18 Department of Health and Children, 'Report of the National Advisory Committee on Palliative Care' (Department of Health and Children 2001) 10; M. McCarron and others, 'Evaluation of the Programme to Support Palliative and Hospice Care in the Republic of Ireland' (Atlantic Philanthropies 2013) 5 'Palliative care principles should be practiced by all healthcare professionals. The palliative care approach should be a core skill of every clinician at hospital and community level. Many patients with progressive and advanced disease will have their care needs met comprehensively and satisfactorily without referral to specialist palliative care units or personnel.'

19 Department of Health and Children (note 18) 31 'The key principles of the palliative care approach include a focus on quality of life, which includes good symptom control; a holistic approach that takes into account the person's life experience and current situation; care that encompasses both the dying person and those who matter to that person; and an emphasis on open and sensitive communication, which extends to patients, carers and professional colleagues.'

20 Ibid. 32; McCarron (note 18) 5; C. Gamondi, P. Larkin and S. Payne, 'Core competencies in palliative care: an EAPC White Paper on palliative care education – part 1' (2013) 20(2) *European Journal of Palliative Care* 86, 87.

21 Department of Health and Children (note 18) 32; McCarron (note 18) 5.

‘devoted to dealing with complex problems requiring specialized skills and competencies’.²² A more detailed explanation is set out by Dixon et al. who state:

Specialist palliative care is provided by multi-disciplinary teams that can include consultants in palliative medicine, nurse specialists, specialist social workers and experts in psychological care. Such staff are specifically trained to provide, and advise on, symptom control and pain relief and other forms of psycho-social and spiritual support.²³

This level of care is provided in settings such as specialist palliative care units, in community settings, and in hospitals. The location where such care is provided will be discussed further in Chapter 1. This discussion will also allow for the distinction between hospice and palliative care to be drawn out.

End-of-life care

The term ‘end-of-life care’ is not synonymous with palliative care.²⁴ Instead, it may include a range of practices beyond palliative care. The precise content of end-of-life care will therefore vary depending on the jurisdiction. In this respect, Clark noted that ‘[e]nd-of-life care may or may not include palliative care or assisted dying.’²⁵ This is an important element to consider when examining the structure of care in different jurisdictions. For instance, Belgium is a jurisdiction where the framework for end-of-life care encompasses palliative care and legally regulated euthanasia. This is described as a model of integral end-of-life care.²⁶ It raises practical questions about the nature of the physician–patient relationship as well as profound questions as to whether such a system conflicts with key palliative principles. Consequently, this work will endeavour to use the term palliative care rather than the more equivocal ‘end-of-life care’.

Euthanasia

The term ‘euthanasia’ has its origins in the Greek term ‘eu thanatos’ which means ‘good or easy death’.²⁷ The interpretation of this term has become much more

22 Gamondi (note 20) 87.

23 J. Dixon and others, ‘Equity in the Provision of Palliative Care in the UK: Review of Evidence’ (London School of Economics, 2015) 16.

24 Ibid. ‘End of life care, with which palliative care can often be confused, refers specifically to care provided in the last phase of life.’

25 D. Clark, ‘Hospice and Palliative Care: Developments, Differences and Challenges’ in S.J. Youngner and R.M. Arnold (eds) *The Oxford Handbook of Ethics at the End of Life* (Oxford University Press 2016) 415.

26 Ibid.; J.L. Bernheim and K. Raus, ‘Euthanasia embedded in palliative care. Responses to essentialist criticisms of the Belgian model of integral end-of-life care’ (2017) *Journal of Medical Ethics* [online].

27 T. Hope, *Medical Ethics: A Very Short Introduction* (Oxford University Press 2004) 11; M. Otłowski, *Voluntary Euthanasia and the Common Law* (Oxford University Press 1997) 4.

8 Introduction

complex and may take several forms. It is an ambiguous term that is often employed in an inaccurate manner.²⁸ This may be due to the various ways in which euthanasia can be categorised. For example, euthanasia may be active²⁹ or passive,³⁰ voluntary,³¹ involuntary³² or non-voluntary,³³ direct³⁴ or indirect³⁵ in nature. The combination of these terms can serve to confuse discussion.

Black's Medical Dictionary defines 'euthanasia' as 'a deliberate act or omission whose primary intention is to end another person's life'.³⁶ This simple definition does not discuss the role capacity has in categorising the form of euthanasia or what such an act or omission may entail. For instance, euthanasia may be by way of a lethal injection, the withdrawal of treatment in certain circumstances, or the provision of drugs that would have the effect of hastening the death of the person.³⁷

Laws prohibiting certain forms of euthanasia have been challenged in several jurisdictions in recent years. This has largely resulted in greater liberalisation of the law surrounding physician-assisted suicide. This practice is permitted, subject to certain controls, in several European countries and US states.³⁸ Physician assisted suicide involves the doctor 'intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent

28 E. Keane, 'Withdrawal of life support for patients in PVS' (2011) 17(2) *Medico-Legal Journal of Ireland* 83, 92; S. Donnelly and S. Purcell, 'The evolution of the law on assisted suicide in the United Kingdom and the possible implications for Ireland' (2009) 15(2) *Medico-Legal Journal of Ireland* 82, 83 'it is necessary to understand the difference between the two concepts of euthanasia and physician assisted suicide which are often mistakenly used interchangeably.'

29 Otowski (note 27) 5 'a deliberate act to end the life of a terminal or incurable patient, which in fact results in the patient's death.'

30 Ibid. 'deliberate withholding or withdrawing of life-prolonging medical treatment or incurable patient, with the object of hastening the patient's death and as a result dies at an earlier time than he or she would have died, had the treatment been carried out.'

31 Ibid. 7 'euthanasia which is performed at the request of the patient. This, in turn, involves an assumption about patient competence and decision-making capacity.'; J. Keown, *Euthanasia, Ethics and Public Policy* (Cambridge University Press 2002) 9 'VAE is generally understood to mean euthanasia at the request of the patient.'

32 Otowski (note 27) 7 'performed without the consent or against the will of a competent patient.'

33 Ibid. 'Euthanasia is "non-voluntary" where it is performed on persons who are incompetent and therefore not capable of giving a consent.'

34 Ibid. 8 'direct euthanasia implies that the intended effect of an act, such as the administration of a dose of narcotic, is to cause the patient's death.'

35 Ibid. 'the same dose may be administered with the same effect, but the intention is to relieve the patient's suffering rather than to kill the patient.'

36 H. Marcovitch (ed.), *Black's Medical Dictionary* (41st edn, A & C Black Publishers 2005) 252.

37 B.A. Garner, *Black's Law Dictionary* (9th edn, Thompson/West 2009) 1571 'providing a person with the medical means or the medical knowledge to commit suicide.'

38 Jurisdictions such as Belgium, the Netherlands, Luxembourg and US states including Oregon, Vermont, Washington and California permit the practice of physician-assisted suicide subject to certain controls.

request'.³⁹ The patient is therefore competent to request death and retains the physical ability necessary to commit suicide. As such, it is not the doctor who performs the act which actually ends the patient's life, although, they do assist the patient in committing suicide. This can be classified as a form of voluntary euthanasia. In sum, there are many variations of euthanasia and subsequent chapters will attempt to reflect these distinctions.

Defining the research boundaries

The parameters of this work are shaped by a combination of social and normative components as well as elements which impact directly on the legal framework in any given jurisdiction. These elements include the increased medicalisation of the dying process, the potential influence of the legal framework, the importance of protecting and promoting human rights, and the legitimacy of the distinction between palliative sedation and certain forms of euthanasia. These are significant factors that have an overarching influence on the provision of palliative care regardless of jurisdiction. They underline the importance of examining this topic but also draw attention to assumptions regarding the practice of palliative care which must be examined as part of this work.

Palliative care has an increasingly important role in healthcare owing to factors such as changing demographics, and an increase in the incidence of cancer and chronic health conditions. Consequently, palliative care is provided to an increasing number of people near the end of life. In 2010, 6% of deaths in Ireland occurred in hospices while 43% occurred in hospitals.⁴⁰ Hospitals and long-stay settings will be placed under greater pressure to care for the dying in the future. The provision of care at the end of life cannot therefore continue to be provided in the same manner. Furthermore, research in Ireland and the UK suggests that a majority of people want to die in their own home but few actually do.⁴¹ There are several possible reasons for this divergence including factors outside the control of the patient. However, evidence from McKeown et al. and the UK National Audit Office suggest that a substantial number of people could have been cared for in locations other than a hospital.⁴² On this point, it has been suggested that 'more

39 L.J. Materstvedt and others, 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force' (2003) 17 *Palliative Medicine* 97, 98; R. O'Connor, 'Physician-assisted suicide: the way forward?' (2004) 22 *Irish Law Times* 182.

40 Irish Hospice Foundation, 'Access to Specialist Palliative Care Services and Place of Death in Ireland' (Irish Hospice Foundation 2013) 11.

41 E. Tiernan and others, 'A prospective study of preferred versus actual place of death among patients referred to a palliative home care service' (2002) 95(8) *Irish Medical Journal* 232; J. Koffinan and I.J. Higginson, 'Dying to be home? Preferred location of death of first-generation black Caribbean and native-born white patients in the United Kingdom' (2004) 7(5) *Journal of Palliative Medicine* 628.

42 K. McKeown, K. Haase and S. Twomey, 'Resources and Facilities for End of Life Care in Hospitals in Ireland' (Irish Hospice Foundation 2010); National Audit Office, 'End of Life Care' (HC1043 Report by the Comptroller and Auditor and General, The Stationery Office 2008).

10 Introduction

could be done to facilitate people to die where they would wish'.⁴³ There are two related points at issue, namely supporting patient preference and the pressures facing the healthcare system. On this basis, it is important that the legal framework is structured in such a manner that it supports the provision of appropriate palliative care across a variety of locations. In order to achieve this, it is essential that there be clarity surrounding the protection of human rights and the legal status of specialist palliative care practices.

The value and role of a clear legal framework has been demonstrated by other areas of medicine such as the use of genetic materials,⁴⁴ and abortion.⁴⁵ The background and development of these areas in medicine underlines the importance of having a well-defined legal framework in place that allows healthcare professionals an unambiguous understanding of the type of care that can be provided to the patient. As such, a legal framework should not function to unnecessarily constrain the decision-making autonomy of doctors. Instead, it should provide clarity as to what objects may be pursued and how this can be achieved for the ultimate benefit of the patient. The challenge of achieving this has been recognised by Quill et al. who noted that:

Similar professional safeguards should be considered for TS (terminal sedation) and VSED (voluntary stopping eating and drinking), even if these practices are already sanctioned by the law. The challenge of safeguards is to be flexible enough to be responsive to individual patient dilemmas and rigorous enough to protect vulnerable persons.⁴⁶

Such an approach may result in a harmonisation of minimum standards of care across healthcare providers. This would be of considerable benefit as over the course of an illness a person will interact with a wide range of healthcare professionals and it is important that the care provided to the patient is at a consistent level and meets clearly identifiable standards. This demonstrates not only how a clear legal framework can be beneficial for healthcare professionals but how it can also benefit the care of the patient.

A high standard of patient care can also be achieved by ensuring that human rights are given effective protection. It is recognised in case law that patients have rights which must be protected. This is further evidenced by protection offered through constitutional provisions, domestic legislation, and international legal instruments such as the European Convention on Human Rights and Fundamental Freedoms. Relevant rights include the right to life, right of autonomy,

43 Irish Hospice Foundation (note 40) 11.

44 The Madden Report on Post Mortem Practice and Procedures (Department of Health and Children 2006).

45 Protection of Life During Pregnancy Act 2013; Abortion Act 1967.

46 T.E. Quill, B. Lo and D.W. Brock, 'Palliative Options of Last Resort: A Comparison of Voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide and Voluntary Active Euthanasia' in T. Tännsjö (ed), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004) 10.

right to bodily integrity, and the protection from inhuman and degrading treatment. In addition, the issue of dignity must be considered. It is necessary to examine how these rights along with the principle of dignity are protected and promoted in the context of specialist palliative care. Patient rights should be to the fore in providing effective and appropriate palliative care. The relevance of human rights to this practice will be underscored by discussion of recent developments in the French legal framework. In France, it would seem that human rights in palliative care have been used as a tool to partly appease groups calling for changes to the law on euthanasia. The potential impact of such an approach will be discussed in Chapter 6.

The majority of palliative care practices do not raise significant legal or ethical concerns. This is not the case for the provision of palliative sedation and the practice of withdrawing artificial nutrition and hydration from the patient. The regulation and standard of professional guidance in this area is particularly important due to the combination of different palliative care providers and the legally, ethically, and clinically complex decisions which have to be made in relation to these palliative care practices by healthcare professionals. The legitimacy of the distinction between specialist palliative care practices and euthanasia has often been called into question, for example, it has been argued that palliative sedation is euthanasia in disguise.⁴⁷ In a similar vein, Boyle commented that ‘some may accept terminal sedation but regard efforts to distinguish it from euthanasia to be sleight of hand’.⁴⁸ The basis for such suggestions will be outlined in Chapter 1 and Chapter 2. The importance of examining specialist palliative care practices has been recognised by Quill et al. who commented that ‘hidden, ambiguous practices, inconsistent justifications, and failure to acknowledge the risks of accepted practices may also undermine the quality of terminal care and put patients at unwarranted risk’.⁴⁹ This work will unpack the criticisms and opaque aspects of these practices. It will also identify and examine the influence of the legal framework in this area. On this point, the chapter structure ensures the legality of specialist palliative care practices is firmly established prior to discussing professional standards and guidelines for palliative and specialist palliative care.

Chapter structure

This work is divided into seven chapters. Chapter 1 of the work provides an introduction to palliative care. The purpose of this chapter is to outline the challenges which arise in the provision of specialist palliative care. It will provide a roadmap for the discussion to take place in later chapters of the work. The first point this chapter will address is the development of palliative care, which requires discussion

47 M.A. Sachs, ‘Sedation – Unconsciousness – Anaesthesia! What are we Talking About?’ in T. Tännsjö (ed.), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004) 31.

48 J. Boyle, ‘Medical ethics and double effect: the case of terminal sedation’ (2004) 25 *Theoretical Medicine* 51, 55.

49 Quill (note 46) 11.

12 *Introduction*

of its historical origins. The chapter then moves on to outline the main locations where palliative care is provided such as hospices, hospitals, and in community settings. This will also outline the evolution of this form of care and will highlight how it is no longer limited to the cancer patient. Instead, it is now of broad applicability and has a correspondingly important role in the healthcare system. The third section in Chapter 1 will address the practices associated with specialist palliative care such as palliative sedation and the withdrawal of artificial nutrition and hydration. This will highlight the controversy surrounding these practices and will underline the importance of examining the legal framework for their provision. The combination of these three sections provides a rounded introduction to the practice and legal challenges of specialist palliative care.

The title of Chapter 2 is ‘Specialist Palliative Care and Euthanasia: A Legitimate Distinction?’ As such, this chapter will engage with the legal and ethical issues raised by specialist palliative care practices. The practice of palliative sedation has previously been described as slow euthanasia and euthanasia in disguise. Thus, the core issue to be addressed in this chapter is the legitimacy of the distinction between specialist palliative care and euthanasia. The starting point in analysing this distinction will be to clarify what euthanasia is. This approach assists in identifying points of similarity and points of departure between the practices. Chapter 2 will then examine the main justifications, which are the doctrine of double effect and the acts and omissions dichotomy. The doctrine of double effect will be outlined and it will be argued that the doctrine can be relied on to support the distinction between euthanasia and specialist palliative care. However, it will be suggested that reliance on the doctrine is no longer appropriate given the realities of medical practice and the role of intention in defining liability under the criminal law. The second point to be addressed is the acts and omissions distinction. This will emphasise the importance of clearly separating the decision to commence palliative sedation from the decision to withdraw artificial nutrition and hydration from the patient. Overall, in Chapter 2 the legitimacy of the distinction between euthanasia and specialist palliative care practices will be clearly demonstrated. In addition, the chapter will begin to emphasise the importance of the legal framework in maintaining the distinction and protecting the principles underpinning palliative care.

Chapter 3 will address the human rights framework for end-of-life care. The impact and relevance of human rights for palliative care has not been considered in previous works on this subject. Nevertheless, human rights have an essential role in shaping the care and treatment provided to the patient at the end of life and it is necessary that this book is cognisant of patient rights. For instance, previous chapters will have highlighted a number of human rights issues such as the need to respect the dignity of the terminally ill patient, access to appropriate palliative care, participation in decision-making, and equality of palliative care provision across different institutions. The discussion of human rights will also inform subsequent chapters which will examine the legal framework for specialist palliative care. The focus will be placed on rights under the European Convention on Human Rights. On this basis, sections in this chapter will consider the right to physical integrity, protection from inhuman or degrading treatment, the right of autonomy, and the

concept of dignity. This chapter does not focus on the theoretical underpinnings of the rights discussed but will mainly concentrate on the manner in which the courts have interpreted and applied these rights. The adoption of this approach allows for the broader legal framework to be examined from a position which focuses on the law in practice. The final section in this chapter will engage with the question of whether there is a right to palliative care. This will also provide an introduction to concerns which arise again in Chapter 6 in the context of recent French legislative developments.

Chapter 4 will examine the regulatory framework for specialist palliative care in England and Wales, and Ireland. The first section in this chapter will address the legal framework in place in England and Wales. This will include discussion of guidance published by the General Medical Council, the National Institute for Health and Care Excellence, and care pathways. Proposed legislation addressing the commissioning and planning of palliative care will also be examined. The chapter will move on to discuss the fragmented legal framework that exists in Ireland. This will involve discussion the Irish Medical Council, the Nursing and Midwifery Board, and guidance issued by bodies such as the Irish Association of Palliative Care and the European Association of Palliative Care. In brief, the chapter will highlight how guidance is being drawn from a range of different sources which has the potential to negatively impact on the provision of palliative care. This results in a piecemeal approach and fails to provide a suitable framework for consistent decision-making.

Chapter 5 will discuss the regulation of palliative care in the Netherlands. This jurisdiction has established detailed professional standards for the provision of palliative sedation rather than pursuing a legislative approach. The introduction of these guidelines was strongly influenced by the need to distinguish specialist palliative care practices from euthanasia. The background to these guidelines will be first set out before moving on to outline the main provisions and consider their impact on end-of-life care in the Netherlands. The impact will be examined through reference to national reports on end-of-life practices in the Netherlands and will draw out larger trends in the provision of specialist palliative care in the jurisdiction.

Chapter 6 will examine the legislative approach to palliative care which is now in place in France. This approach stands in contrast to the regulatory framework adopted in the Netherlands. The French ‘loi sur la fin de vie’ establishes a right to request palliative sedation, an approach which has not been adopted in any other jurisdiction. The discussion surrounding the legislation in France was closely tied to broader arguments about the legal status of euthanasia. As such, the background to the legislation and the background to palliative care provision in the jurisdiction will be discussed. The chapter will examine the introduction and debates surrounding the French ‘loi sur la fin de vie’ before discussing the potential impact of recognising a right to request palliative sedation. The chapter will argue that this legislation has the potential to impact negatively on the patient–doctor relationship and has serious consequences for the legitimacy of the distinction between euthanasia and specialist palliative care.

14 *Introduction*

The final chapter will present a summary of the main conclusions advanced over the course of the monograph. This chapter will also present arguments as to how the legal framework for palliative care could develop in the future in order to maintain the legitimacy of the distinction between specialist palliative care practices and euthanasia, while also protecting and promoting the patient's human rights.

1 The development and practice of palliative care

1.0 Introduction

Care for a person at the end of life has developed considerably in recent decades. Its development has been influenced by clinical, social, and cultural elements. The interplay of which has resulted in the emergence of legal and ethical issues which push at the boundaries of what constitutes appropriate end-of-life care. These challenges are exacerbated by debates surrounding suitable terminology, the framing of definitions, the status of ethical justifications, and even what role should palliative care have in relation to broader end-of-life practices. There is no simple or definitive answer for many of these issues. Instead, this chapter will outline the development and practice of palliative care, and in doing so, will begin to tease out the central concepts which inform and underpin its practice. This can provide the basis for clearer analysis and discussion. This approach will highlight diverging perspectives on palliative care practices, underline points of legal and ethical contention, and will illuminate areas where the legal framework has a significant role in shaping the practice of palliative care.

Over the course of three sections, this chapter will discuss the development and practice of palliative care in general and as it is currently provided in the United Kingdom, Ireland, and in other European countries. The evolution of palliative care will be discussed in the first section. This discussion will focus on the origins of palliative care and the organisations which have led the promotion and provision of palliative care. The emergence of modern palliative care as a distinct form of care will be highlighted. The advent of modern palliative care reflects an holistic approach to patient care as well as a more focused approach to pain management. A significant shift in the development of palliative care is that it is no longer limited to the cancer patient. It is now of broad applicability and has a correspondingly important role in the healthcare system. Different illnesses raise distinct problems but over the course of this section key overlapping challenges to the provision of palliative care will be identified.

The provision of palliative care is considered in the second section of this chapter. Hospices, hospitals, and palliative care in a community setting will be discussed. This will illustrate the growth in palliative care and it raises the question of whether the current legal framework in the UK and Ireland for specialist

palliative care is adequate given the breadth of palliative care providers and the treatment which they provide. This section also underlines the argument that palliative care has largely developed through the actions of representative bodies and charitable organisations rather than being driven by state led initiatives.

The third section explores the practices closely associated with specialist palliative care, namely palliative sedation and artificial nutrition and hydration. This section will highlight the ongoing debate surrounding these practices and will demonstrate the importance of examining the legal framework for their provision. For instance, these practices represent a key aspect of specialist palliative care and it is important for both the patient and the healthcare professional that the legal framework is clear, consistent, and protects the patient's human rights. The combination of these three sections provides a rounded introduction to the development and practice of palliative care in the UK and Ireland as well as highlighting the legal and ethical issues which later chapters will address.

1.1 The development of hospice and palliative care

The development of palliative care as a distinct form of care is closely linked to oncology and care of the cancer patient.¹ This becomes clear in considering the background to the early providers of care at the end-of-life such as hospices. The word 'hospice' is derived from the Latin word 'hospes' which translates as host, guest or stranger.² Accordingly, between the 11th and 18th centuries the term hospice referred to 'a place of shelter for pilgrims and travellers'.³ This understanding of the term began to change when in 1842 Mme Jeanne Garnier founded the Dames du Calvaire in Lyon which provided care for the dying. The term 'hospice' was applied to this form of care which was marked by 'a respectful familiarity, an attitude of prayer and calm in the face of death'.⁴

In Ireland, hospices were opened in Cork and Dublin in the 19th century. Marymount Hospice in Cork opened in 1870 and originally cared for cancer and tuberculosis patients.⁵ In 1879, the Congregation of the Religious Sisters of

1 D. Clark, 'From margins to centre: a review of the history of palliative care in cancer' (2007) 8 *Lancet Oncology* 430, 430.

2 J.R.V. Marchant and J.F. Charles, *Cassell's Latin Dictionary (Latin-English and English-Latin)* (Cassell and Company 1948) [hospes] 254; M. de Vaan, *Etymological Dictionary of Latin and the other Italic Languages* (Brill 2008) [hospes] 291.

3 Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003, 19.

4 D. Clark, 'Palliative care history: a ritual process?' (2000) 7(2) *European Journal of Palliative Care* 50, 51; S.L. Ragan and others, *Communication as Comfort: Multiple Voices in Palliative Care* (Taylor & Francis 2008) 22 'The term was first used by Madame Jeanne Garnier [sic] who founded the Dames de Calaire in Lyon, France in 1842.'

5 K. McCarthy, *A Dream Unfolding: Portrait of St Patrick's Hospital & Marymount Hospice* (St. Patrick's Hospital/Marymount Hospice 2004) 43.

Charity (Irish Sisters of Charity) established Our Lady's Hospice in Dublin.⁶ This hospice originally concentrated on the care of patients with tuberculosis but near the end of the 1950s more and more cancer patients were admitted. These hospices cared for patients who were not admitted to hospital. An inability to pay for care, lack of appropriate facilities, or the worry that infection would be transmitted to other patients were among the reasons for a patient being refused care in a hospital.⁷ Consequently, hospices began to take on a distinct role in the care of the terminally ill patient; a role which hospitals were unwilling and/or unable to provide at the time.

The Irish Sisters of Charity were also instrumental in the development of hospice care in England as this congregation was involved in the founding of St Joseph's Hospice in London in 1905.⁸ The background to the founding of these early hospices reveals certain common characteristics. They grew from a combination of altruistic contributions, religious influence, and moral concerns.⁹ Despite the close religious ties of these early hospices, care was available for those of any or no religious belief.¹⁰ Nevertheless, there were limits to what could be achieved by this early form of hospice care.¹¹

The standard of care for the dying person was restricted by the level of medical knowledge on pain management,¹² and the lack of appropriate drugs.¹³ A culture of research into end-of-life care and pain management began to emerge in the 1950s, as signalled by research on cancer carried out by Bailey,¹⁴ Aitken-Swan¹⁵ and, in particular, Dame Cicely Saunders.¹⁶ It was in St Joseph's Hospice where

6 Our Lady's Hospice & Care Services, 'Our Heritage' <<http://www.olh.ie/6-about-us/38-our-heritage/>> accessed 7 February 2017.

7 Ibid.

8 N. Milićević, 'The hospice movement: history and current worldwide situation' (2002) 10(1) *Archive of Oncology* 29, 30.

9 D. Clark, 'Hospice and Palliative Care: Developments, Differences, and Challenges' in S.J. Youngner and R.M. Arnold (eds), *The Oxford Handbook of Ethics at the End of Life* (Oxford University Press 2016) 412.

10 J. Gilbert, 'Palliative medicine: a new specialty changes an old debate' (1996) 52(2) *British Medical Bulletin* 296, 299. 'Even the most overtly religious hospices are at pains to make clear that those of any faith, and those of none, are welcomed.'

11 Clark (note 9) 412 'They were not, however, places in which the medical or nursing care of the dying was of any real sophistication.'

12 Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003, 19.

13 Ibid.

14 M. Bailey, 'A survey of the social needs of patients with incurable lung cancer' (1959) 11 *The Almoner* 379.

15 R. Paterson and J. Aitken-Swan, 'Public opinion on cancer; a survey among women in the Manchester area' (1954) 23 *Lancet* 857; J. Aitken-Swan and R. Paterson, 'The cancer patient: delay in seeking advice' (1955) 1 *British Medical Journal* 623.

16 C. Saunders, 'Drug treatment of patients in the terminal stages of cancer' (1960) 1(1) *Current Medicine and Drugs* 16; C. Saunders, 'The symptomatic treatment of incurable malignant disease' (1964) 4 *Prescriber's Journal* 68; C. Saunders, 'The care of the terminal stages of cancer' (1967) 41 *Annals of the Royal College of Surgeons* 162.

Dame Cicely Saunders began her clinical research in 1958.¹⁷ Research was also being conducted in the United States around this time, particularly by Elisabeth Kübler-Ross, which would prove influential in shaping the debate on care of the dying person in the US.¹⁸ Kübler-Ross sought to promote more open discussion at the end of life and addressed the reticence which isolated the dying person from their carers and those around them.

The research led to a greater understanding of the care required for cancer patients and, ultimately, resulted in infrastructural changes which were a sea-change in caring for the dying. In this regard, Dame Cicely Saunders founded St Christopher's Hospice in London in 1967 which marked the beginning of modern hospice care.¹⁹ St Christopher's Hospice signalled a more focused attempt to manage and understand the nature of pain experienced by the patient. For instance, research was carried out on methods of pain relief such as the Brompton Cocktail,²⁰ and the concept of 'total pain' was identified. Total pain recognises the multi-faceted nature of pain including its physical symptoms, as well as emotional, social, and spiritual components.²¹ Adequately treating such pain is a complex task which requires careful assessment of the patient and an awareness of the limits of various forms of care. The healthcare professional is required to take account of each of the components and by doing so 'could almost get total pain control'.²²

The research conducted in St Christopher's Hospice was valuable in understanding the effect and role of drugs for pain relief, as evidenced by subsequent World Health Organization engagement on this subject.²³ This included the

17 St Joseph's Hospice, 'Our history' <<https://www.stjh.org.uk/about-us/our-history>> accessed 7 February 2017.

18 Elisabeth Kübler-Ross, *On Death and Dying* (Tavistock 1969).

19 St Christopher's Hospice, 'History' <<http://www.stchristophers.org.uk/about/history>> accessed 7 February 2017.

20 R. Twycross, a Clinical Research Fellow in St Christopher's Hospice, conducted research into methods of pain relief such as the Brompton Cocktail. R. Twycross 'Choice of strong analgesic in terminal cancer: diamorphine or morphine?' (1977) 3 *Pain* 93; R. Twycross, 'The Brompton Cocktail' in J.J. Bonica and V. Ventafridda (eds), *International symposium on pain of advanced cancer* (Vol. 2, Raven Press 1979); See also D. Clark, 'The Rise and Demise of the "Brompton Cocktail"' in M.L. Meldrum (ed.), *Opioids and Pain Relief: A Historical Perspective* (IASP Press 2003).

21 Saunders (note 16); C. Saunders, 'The evolution of palliative care' (2001) 94(9) *Journal of the Royal Society of Medicine* 430; McGill, 'Palliative Care McGill: Balfour Mount' <<https://www.mcgill.ca/palliativecare/portraits-0/balfour-mount>> accessed 19 March 2017. Balfour Mount described the concept of 'total pain' as Cicely Saunders' 'most significant contribution'.

22 McGill, 'Palliative Care McGill: Balfour Mount' <<https://www.mcgill.ca/palliativecare/portraits-0/balfour-mount>> accessed 19 March 2017.

23 World Health Organization, 'The Solid Facts: Palliative Care' (World Health Organization 2004) 7 'One powerful element of the work that developed into the whole spectrum of palliative care was a breakthrough in the attitude to pain, as it became recognized in all its complexity in the 1960s. It began with a concentration on cancer pain. This focus made possible the early research that led to the booklet *Cancer Pain Relief*, published by WHO in 1986.'

publication of ‘Cancer Pain Relief’²⁴ which set out a three-step analgesic ladder; the third step being the use of strong opioids. The availability of opioids for pain relief was among the early concerns of the World Health Organization in relation to palliative care and led to ‘an international initiative to remove legal sanctions against opioid importation and use’.²⁵ The availability of opioids is not an isolated issue to be addressed in the legal framework. A closely related point to emerge is the appropriate use of opioids given their potential to bring about death. These points highlight the role of a legal framework in influencing and shaping clinical aspects of end-of-life care.

The work of St Christopher’s Hospice also informed the development of hospice and palliative care internationally. St Christopher’s Hospice hosted practitioners from other jurisdictions who subsequently applied the knowledge and experience gained to caring for the dying in their own country. Balfour Mount, a urological surgeon from Canada, visited St Christopher’s Hospice in September 1973 and went on to establish a unit in the Royal Victoria Hospital Montreal and coin the term ‘palliative care’.²⁶ This was more than a mere change in terminology and signalled a broader application of the hospice philosophy and ‘an expanded clinical ambition’.²⁷ Similarly, the visit of Gustavo de Simone resulted in the founding of the Pallium organisation in Argentina and he went on to be a key figure in the development of palliative care in South America.²⁸ This underlines how hospice and palliative care often developed through the work of individuals and charitable organisations rather than through direct state involvement. Nonetheless, hospice and palliative care services continued to expand. Research by the International Observatory on End of Life Care suggested that in 2011 ‘136 of the world’s 234 countries (58%) had one or more hospice-palliative care services established’.²⁹ These services are at varying degrees of maturity and are shaped by the cultural context and normative values in each jurisdiction. These factors must be kept in mind in subsequent chapters when examining the role and potential limits of the legal framework for palliative care. Moreover, these figures draw attention to the distinction which exists between hospice and palliative care.

1.1.1 The emergence of modern palliative care

Modern palliative care emerged in the UK and Ireland in the 1980s.³⁰ This was marked by changes in medical practice, the establishment of support and professional

24 World Health Organization, ‘Cancer Pain Relief’ (World Health Organization 1986).

25 Clark (note 1) 433.

26 M. Baines, ‘From pioneer days to implementation: lessons to be learnt’ (2011) 18(5) *European Journal of Palliative Care* 223, 227; Clark (note 9) 414.

27 Clark (note 9) 414.

28 Baines (note 26) 227.

29 T. Lynch and others, ‘Mapping levels of palliative care development: a global update’ (2013) 45(6) *Journal of Pain and Symptom Management* 1094, 1098.

30 Department of Health and Children, ‘Report of the National Advisory Committee on Palliative Care’ (Department of Health and Children 2001) 21.

organisations, the creation of consultant and leadership positions in palliative medicine, and the recognition of palliative medicine as a distinct medical specialty.

Changes in medical practice are demonstrated by the broader application of the principles of hospice care. In the years after the opening of St Christopher's Hospice the focus of care began to include those at an earlier stage in the disease trajectory and addressed a broad range of concerns such as quality of life and improved care management.³¹ There was also a significant increase in the provision of palliative care services so much so that this time has been described as a 'golden period of such growth' in the UK.³² For instance, in the years 1982 to 1996 the presence of a multidisciplinary palliative care team or specialist palliative care clinical nurse within a hospital setting increased from five to 275.³³

Owing to the development and increase in the number of hospices and organisations providing palliative care it is not surprising that support and professional organisations emerged. The Association for Palliative Medicine for Great Britain and Ireland was established in 1985 and serves as a 'representative body for doctors practicing or interested in Palliative Medicine'.³⁴ The founding of the Association involved Derek Doyle, Robert Twycross, and Richard Hillier. It is notable that this organisation settled on the term 'palliative' rather than 'hospice' particularly as this form of care was in the early stages. Moreover, it is the term 'terminal care' which is used at several points in the minutes of the inaugural meeting.³⁵ In any case, there were significant political and professional motivating factors which influenced the establishment of this organisation. Several umbrella charities such as the National Council for Palliative Care have since emerged. This body represents people and organisations involved in the provision of various forms of care at the end of life including palliative and hospice care in England, Wales, and Northern Ireland. Scotland is covered by the Scottish Partnership for Palliative Care which was established in 1991.

In Ireland, a specialist palliative care unit was established in Marymount Hospice in Cork in 1980.³⁶ The position of consultant physician in palliative medicine was first created in 1989,³⁷ and in 1986 the Irish Hospice Foundation ['IHF'] was established.³⁸ The IHF is a voluntary support organisation which promotes

31 Clark (note 9) 414 'care management, quality of life, better coordination of care, and a desire to match patients' and families' needs and preferences to actual experiences'.

32 Clark (note 1) 432.

33 Ibid. 432–433.

34 Association for Palliative Medicine, 'Welcome' <<http://apmonline.org/>> accessed 7 February 2017.

35 C. Overy and E.M. Tansey (eds), 'Palliative Medicine in the UK c.1970–2010' Wellcome Witnesses to Twentieth Century Medicine (Queen Mary, University of London 2013).

36 McCarthy (note 5).

37 D. Rowe and others, 'Palliative Care Teamwork in the Republic of Ireland –The Key to Physical and Psychological Function' in J. Ling and L. O'Síoraín (eds), *Palliative Care in Ireland* (Open University Press 2005) 85.

38 Irish Hospice Foundation, 'About Us' <<http://hospicefoundation.ie/about-us/>> accessed 7 February 2017.

the development and advancement of hospice services in Ireland. The early work of the IHF included raising money for research and training,³⁹ developing hospice home-care services⁴⁰ and eventually the opening of a number of hospices.⁴¹ In recent years, the IHF has established several programmes aimed at improving the provision of palliative care such as 'Hospice Friendly Hospitals',⁴² the 'Palliative Care for All' programme⁴³ and the 'Primary Palliative Care' programme.⁴⁴ These programmes along with the investment in research, training, and hospice development demonstrate the influence of the IHF in developing modern palliative care in Ireland. Despite the considerable impact of the IHF, they were not the only body which contributed to the development of palliative care in Ireland. Palliative care continued to develop in Ireland in the 1990s as demonstrated by the establishment of the Irish Association of Palliative Care ['IAPC'] in 1993. The IAPC is 'an all island body with the purpose of promoting palliative care nationally and internationally'⁴⁵ and its members come from a range of disciplines. The work of the IAPC has included publishing position and discussion papers on artificial hydration,⁴⁶ voluntary euthanasia,⁴⁷ and palliative sedation.⁴⁸ These will be referred to in Chapter 4 of this work.

Outside the confines of the UK and Ireland, several international palliative care groups formed. At a European level, the European Association of Palliative Care ['EAPC'] was established in 1988. At the time of writing it has 58 member organisations from 32 European countries as well as individual members from 48 countries across the world.⁴⁹ The organisation has published multiple recommendations, white papers, and statements. The practice and formal recognition of palliative medicine has spread beyond Europe and several international palliative care groups were formed in the early 2000s. The Latin American Association of Palliative Care was established in 2000. The Asia Pacific Hospice Palliative Care Network was set up in 2001 and represents 14 countries. While in 2002 the

39 P. O'Morain, 'The Irish Hospice Foundation 1986–2006: The First 20 Years' (Irish Hospice Foundation 2006) 10.

40 Ibid. 11.

41 Ibid. 16.

42 Irish Hospice Foundation, 'Hospice Friendly Hospitals Programme' <<http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/>> accessed 7 February 2017.

43 Irish Hospice Foundation, 'Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks' (Irish Hospice Foundation 2008).

44 Irish Hospice Foundation, 'Primary Palliative Care in Ireland' (Irish Hospice Foundation 2011).

45 Irish Association of Palliative Care, 'What does the Irish Association of Palliative Care do?' <<http://www.iapc.ie/what-we-do.php>> accessed 7 February 2017.

46 Irish Association of Palliative Care, 'Artificial Hydration in Terminally Ill Patients' (Irish Association of Palliative Care 2011).

47 Irish Association of Palliative Care, 'Voluntary Euthanasia' (Irish Association of Palliative Care 2011).

48 Irish Association of Palliative Care, 'Palliative Sedation' (Irish Association of Palliative Care 2011).

49 European Association of Palliative Care, 'About the EAPC' <<http://www.eapcnet.eu/Corporate/AbouttheEAPC.aspx>> accessed 19 March 2017.

African Palliative Care Association was founded and serves to act as a hub and focal point to encourage the dissemination of palliative care services across the continent. Among the early work of the African Palliative Care Association was the Cape Town Declaration which set out that '[p]alliative care is a right of every adult and child with a life-limiting disease'⁵⁰ and '[t]he control of pain and symptoms is a human right, and therefore, appropriate drugs should be available in every country in sub-Saharan Africa as part of the essential drug list, including opioids such as morphine.'⁵¹ The effect of such a declaration will be considered in Chapter 3 along with the Korea Declaration,⁵² and the Prague Charter.⁵³

The recognition of palliative medicine as a medical specialty was a considerable step in signalling the prominence of modern palliative care. Such recognition is evidence of 'a clearly defined patient population, clearly defined disease processes, and clearly defined research interests'.⁵⁴ In the UK this recognition was linked with the work of the Association for Palliative Medicine for Great Britain and Ireland as referenced above. The possibility of establishing palliative medicine as a specialty was proposed by Gillian Ford, the Deputy Chief Medical Officer for England, in a paper for the JCHMT.⁵⁵ This suggestion ultimately led to the recognition of palliative medicine as a subspecialty of general medicine in 1987.⁵⁶ This recognition was originally on a seven-year 'novitiate' which resulted in the establishment of the medical specialty.

In 1995 the Irish Medical Council recognised palliative medicine as a medical specialty. Palliative medicine has since been recognised as a medical specialty in Malta in 2003, Poland in 1999, Australia in 2004, and Slovakia in 2012. It has been recognised as a subspecialty in far more jurisdictions including Canada, Czech Republic, Georgia, Germany, Hungary, Israel, Romania, and the USA.⁵⁷ In addition to this, palliative medicine has received special denomination in Denmark, Finland, France, Italy, Latvia, Norway, Portugal, and Slovakia. This undoubtedly

50 (–) 'The Palliative Care Trainers Declaration of Cape Town' (2003) 6(3) *Journal of Palliative Medicine* 339.

51 Ibid.

52 Korea Declaration (National Hospice and Palliative Care Associations 2005).

53 Prague Charter.

54 R.C. Wetzel and C.E. Nicholson, 'Research in Pediatric Critical Care' in B.P. Fuhrman and others (eds), *Pediatric Critical Care* (4th edn, Elsevier 2011) 41.; See also D. Doyle, 'Palliative Medicine: the first 18 years of a new sub-specialty of General Medicine' (2005) 35 *Journal of the Royal College of Physicians* 199.

55 D. Clark, 'Palliative medicine as a specialty' (30 June 2014) <<http://endoflifestudies.academicblogs.co.uk/palliative-medicine-as-a-specialty/>> accessed 20 March 2017. 'Gillian Ford prepared a paper for the JCHMT and at the same time encouraged the chairman of the Specialty Advisory Committee in General Medicine and other senior medical colleagues to visit St Christopher's for an appreciation of the work being done there.'

56 Doyle (note 54) 'Palliative Medicine: the first 18 years of a new sub-specialty of General Medicine' (2005) 35 *Journal of the Royal College of Physicians* 199.

57 D. Bolognesi and others, 'Specialisation in Palliative Medicine for Physicians in Europe: A supplement of the EAPC Atlas of Palliative Care in Europe (EAPC Press 2014).

illustrates the level of recognition and status now accorded to palliative medicine. However, underlying issues and debates persist. These include questions about the correct classification of palliative medicine, the balance in addressing physical and psychosocial symptoms, and definitional challenges. Regardless, palliative care has continued to expand beyond its oncological origins, as reflected by the patient population it now serves.⁵⁸

1.1.2 Expansion in categories of palliative care patients

The close link between the development of palliative care and oncology allowed for a focused approach to the development and understanding of palliative care but limited its broader application for several years. Palliative care is no longer limited to patients with a cancer diagnosis. Instead, it has expanded to provide care for people suffering from a wide range of serious illnesses.⁵⁹ Palliative care may be provided to patients suffering from motor neurone disease,⁶⁰ AIDS,⁶¹ chronic obstructive pulmonary disease,⁶² chronic kidney disease,⁶³ dementia,⁶⁴ or it may be provided to older people based on their medical condition.⁶⁵ This expansion in palliative care patients did not happen instantly but was often a response to increased demand from patient populations whose care needs were not being adequately met.⁶⁶

58 Clark (note 1) 437 'As cancer patients become increasingly likely to have access to appropriate care at the end of life, another huge challenge now awaits: the delivery of expert palliative care to those with non-malignant disease.'

59 M. Gott and others, "'That's part of everybody's job": the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care' (2012) 26(3) *Palliative Medicine* 232, 232–233 'Indeed, in a relatively short space of time, palliative care has developed from being viewed as synonymous with terminal care for cancer patients, to being regarded as having relevance at an early stage in the disease process of anyone whose death can be medically anticipated.'

60 D. Oliver, 'Palliative care for Motor Neurone Disease' (2002) 2 *Practical Neurology* 68.

61 R. Harding and others, 'Access and equity in HIV/AIDS palliative care: a review of the evidence and responses' (2005) 19(3) *Palliative Medicine* 251.

62 C.M. Roberts and others, 'Clinician perceived good practice in end-of-life care for patients with COPD' (2008) 22 *Palliative Medicine* 855; R. Harding and others, 'Provision of palliative care for chronic heart failure inpatients: how much do we need?' (2009) *BMC Palliative Care* 8.

63 S.N. Davison and C.J. Ferro, 'Management of pain in chronic kidney disease' (2009) 17(4) *Progress in Palliative Care* 186.

64 E.L. Sampson and others, 'Palliative care in advanced dementia; A mixed methods approach for the development of a complex intervention' (2008) *BMC Palliative Care* 8.

65 National Council on Ageing and Older People, 'End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland' (National Council on Ageing and Older People 2008).

66 J. Addington-Hall and K. Hunt, 'Non-cancer Patients as an Under-served Group' in Joachim Cohen and Luc Deliens (eds) *A Public Health Perspective on End of Life Care* (Oxford University Press 2012) 152 'The rapid growth in the number of people affected by AIDS/HIV in the USA, Europe and the UK in the 1980s also challenged the focus of hospices on cancer.'

The variety of illnesses for which palliative care may be provided raises a number of challenges. Among these is the need to assess the patient's disease trajectory.⁶⁷ This is a relevant concern for all illnesses as it impacts on the decision to commence palliative care and, accordingly, the level of palliative care which is to be provided. It has previously been set out that specialist palliative care is of most relevance near the end of the patient's life however '[a] hard and fast objective clinical distinction as to when the dying process commences is not always possible'.⁶⁸ This lack of a bright-line test is particularly difficult in relation to non-cancer patients.⁶⁹ As a consequence of this, it is often a more difficult task to identify a non-cancer patient as being close to the end of life. This can result in limiting access to palliative care for patients experiencing heart failure or chronic obstructive pulmonary disease.⁷⁰ It also illustrates the wider difficulty in making decisions in relation to this form of care.

A study by O'Leary and Tiernan of specialist palliative care in Ireland revealed that 24% of specialist palliative care services restricted care for noncancer patients in some manner.⁷¹ In instances where care was available to noncancer patients, the type of care was 'the same as for cancer patients in 81% of services'.⁷² Nonetheless, the research demonstrated that in 2004, 7.21% of patients cared for by specialist palliative care services had an illness other than cancer.⁷³ The research also highlighted a number of barriers to the expansion of palliative care including 'the unpredictable non-cancer disease trajectory, the resultant difficulties with developing referral criteria and the lack of noncancer disease specific expertise'.⁷⁴ There are therefore both intrinsic and extrinsic barriers to be addressed in the promotion and development of palliative care in specialist facilities. Some of these difficulties relate to clinical limitations while several are influenced by the level of knowledge which healthcare professionals have about the role of palliative care and the clarity in referral criteria for such care.⁷⁵ The prevalence of such challenges in the context

67 S.J. Swart and others, 'Continuous palliative sedation for cancer and noncancer patients' (2012) 43(2) *Journal of Pain and Symptom Management* 172, 179 'in non-cancer patients, end-of-life disease trajectories often involve a rather long-term fluctuating process of gradual decline punctuated by episodes of acute deterioration and eventually a seemingly unexpected death.'

68 M. Ashby and B. Stoffell, 'Artificial hydration and alimentation at the end of life: a reply to Craig' (1995) 21(3) *Journal of Medical Ethics* 135, 137.

69 D. Field and J. Addington-Hall, 'Extending specialist palliative care to all?' (1999) 48 *Social Science and Medicine* 1271, 1275.

70 Roberts (note 62); Addington-Hall (note 66) 156 'This effectively excluded patients on, for example, the organ failure trajectory whose prognosis was much less certain. There remains a lack of good prognostic indicators in, for example, congestive (CHF) and COPD.'

71 N. O'Leary and E. Tiernan, 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers' (2008) *Palliative Medicine* 77, 77.

72 Ibid.

73 Ibid.

74 Ibid. 79–80.

75 Ibid. 81 'The lack of explicit written referral policies in 31% of services in Ireland in 2005 is surprisingly high. Only 22 services (35%) have a written referral policy that

of specialist palliative care raises questions about how these issues are addressed in other locations where forms of palliative care are provided.

Overall, the growth and evolution of palliative care underlines its role and status in healthcare. It is a practice which continues to develop but faces barriers including social and policy constraints. In response to such barriers there are several points in this section which must be taken into account. The first point is the importance of ensuring access to appropriate palliative care regardless of the underlying illness. In effect, care of the person is central. The second point to note relates to the concept of total pain. Adequately responding to total pain calls for a sophisticated and clinically challenging response which requires healthcare professionals to be cognisant of the limits of their professional competencies. The care of patients will often require a multidisciplinary approach. This is essential in ensuring appropriate care. As such, not all pain should be treated as physical pain would. In this respect, it is important that as palliative care develops it guards against a culture of silence which would dissociate the patient from their care. The development of palliative care may well signal a shift in the *ars moriendi* and the form this takes will be influenced by the providers and practice of palliative care.

1.2 Palliative care providers

Palliative care in the UK and Ireland is provided in locations such as hospices, hospitals, and in community settings where care is regularly supported by primary care infrastructure. Infrastructure and geographical factors therefore have a considerable influence on the availability of care. While it is difficult to draw specific conclusions about providers of palliative care in the confines of this section, broad themes do emerge. Discussing these providers facilitates the later identification of the legal framework in jurisdictions such as the UK and Ireland. It also ensures that the analysis of the legal framework takes account of the intricate relationship between the various providers of palliative care.

1.2.1 Hospice care

Palliative care may be provided from an early point in the disease trajectory whereas inpatient hospice care generally signals a significant shift in the treatment of the patient from cure to care. An EAPC white paper set out that '[a]n inpatient hospice admits patients in their last phase of life, when treatment in a hospital is not necessary and care at home or in a nursing home is not possible.'⁷⁶ The care provided is multidisciplinary with a core team of nurses and access to a physician.

made explicit reference to noncancer patients.'; Lieve Van den Block, 'Palliative Care in Primary Care' in Joachim Cohen and Luc Deliens, *A Public Health Perspective on End of Life Care* (Oxford University Press 2012) 118 'referral criteria vary across countries or are not always explicit'.

76 European Association of Palliative Care, 'White Paper on standards and norms for hospice and palliative care in Europe: part 2' (2010) 17(1) *European Journal of Palliative Care* 22, 28.

The role of hospices has expanded over time. In addition to dedicated inpatient hospice care, hospices regularly provide a range of services to support the patient including respite care and the provision of home nursing teams. In this sense, hospices have a vital role in providing and developing care for the person at the end-of-life.

The establishment of hospices was largely led by charitable organisations and religious institutions as was noted earlier.⁷⁷ As a result, there was no central plan for the development and expansion of this form of care. The provision of hospice care in jurisdictions such as Ireland can be viewed as sporadic and has resulted in certain 'geographical regions without an inpatient hospice to serve as the hub around which comprehensive community services can develop'.⁷⁸ This has been highlighted by the Irish Hospice Foundation as a key challenge to the development of palliative care.⁷⁹ It has also been highlighted as an issue facing locations such as the North West of England.⁸⁰ In essence, a geographical lacuna in hospice services can serve to place greater responsibility and pressure on local general practitioners and hospitals to provide appropriate care for the patient.⁸¹

Admission to a hospice may be organised through a patient's general practitioner. Patients who are already receiving care in a hospital may be referred by the consultant in charge. In order for this process to be effective there must be a common understanding of palliative care among healthcare professionals. There must also be clear referral criteria. The absence of such criteria represents a substantial barrier to the greater provision of specialist palliative care.⁸² In such circumstances, the patient may not be referred to the appropriate palliative care services in a timely manner. This may also have the effect of undermining a patient's involvement in later decisions relating to their healthcare depending on the disease trajectory. A shared understanding of the role and limits of palliative care practices is therefore essential.

1.2.2 Hospitals

Hospitals are generally less associated with the provision of specialist palliative care. Hospitals are seen as focusing on curative treatments whereas specialist

77 Hospice UK, 'Facts and Figures' <<https://www.hospiceuk.org/media-centre/facts-and-figures>> accessed 21 March 2017.

78 Irish Hospice Foundation, 'Strategic Plan: 2012–2015' (Irish Hospice Foundation 2012) 8.

79 Ibid.

80 J. Wood and T. Gartrell, 'Equity of Geographical Access to Inpatient Hospice Care Within North West England: A Geographical Information Systems (GIS) Approach' (North West Public Health Observatory 2002).

81 EAPC European Journal of Palliative Care (2010) 17(1) 24 – 'There should be at least one specialist palliative care inpatient unit within each healthcare service area. The specialist palliative care inpatient unit should be the core element of the specialist palliative care service. Specialist palliative care services in all other settings, including general hospitals and the community, should be based in, or have formal links with, the specialist palliative care inpatient unit. This connection not only warrants support and continuing education of the teams, but also improves continuity in patient care.'

82 O'Leary (note 71) 79–80.

palliative care signals a change in the condition of the patient to a point where curative treatment is no longer a reality.⁸³ This view of hospitals tends to neglect the fact that they are one of the most common places of death as demonstrated by mortality figures in Ireland and in England.⁸⁴ There have been moves towards increasing the role hospitals have in the provision of various forms of palliative care including specialist palliative care. The implementation of palliative care programmes in a hospital setting is increasingly prevalent in the United States, Australia, and the United Kingdom.⁸⁵ The expansion of palliative care delivery in such facilities is shaped by physical infrastructure, the level of knowledge about palliative care among healthcare professionals, and the presence and support of palliative care teams.⁸⁶ These teams serve an important role in ensuring appropriate palliative care provision can be provided in a hospital setting. The hospital palliative care support team serves to 'provide specialist palliative care advice and support to other clinical staff, patients and their families and carers in the hospital environment. They offer formal and informal education, and liaise with other services in and out of the hospital.'⁸⁷ The hospital palliative care team can therefore contribute to the standard of care as well as facilitating the move between inpatient and outpatient care.⁸⁸

The United States has been particularly active in developing hospital-based palliative care. This is demonstrated by a 2010 survey in the US which indicated that '60% of hospitals with 50 or more facility beds reported having hospital palliative care services.'⁸⁹ In contrast to this, Rocafort et al., noted that outside of the US, the presence of hospital-based palliative services is 'highly variable with relatively high penetration in Canada, Australia, New Zealand, Israel, and parts of Europe (e.g. the U.K., Belgium, Norway, Germany), more modest penetration in countries such as Taiwan, Japan, Europe (e.g. the Netherlands, Poland, Portugal), and

83 Task Force on Palliative Care, Last Acts Campaign, and Robert Wood Johnson Foundation, 'Precepts of palliative care' (1998) 1(2) *Journal of Palliative Medicine* 109, 110.

84 K. McKeown, 'Key Performance Indicators for End-of-Life Care: A Review of Data on Place of Care and Place of Death in Ireland' (Irish Hospice Foundation, 2012) In Ireland, 43% of deaths occur in acute hospitals; National End of Life Care Intelligence Network, 'Data Sources' <http://www.endoflifecare-intelligence.org.uk/data_sources/place_of_death> accessed 25 March 2017.

85 A. Kelley and others, 'Palliative Care in Hospitals' in J. Cohen and L. Deliens, *A Public Health Perspective on End of Life Care* (Oxford University Press 2012) 135 'Hospitals with early hospital-based palliative care services included St Luke's Hospital in New York, McGill's Royal Victoria Hospital in Montreal, St Thomas's Hospital in London, and the National Cancer Institute in Milan.'; Care Quality Commission, 'The state of care in NHS acute hospitals: 2014 to 2016' (Care Quality Commission 2017) 79 Several examples of 'outstanding practice' are provided.

86 Kelley (note 85) 135 The palliative care team may also be referred to as 'terminal care support team, symptom control team, supportive care team, and comfort care team'.

87 European Association of Palliative Care (note 76) 28.

88 Ibid. 29.

89 Kelley (note 85) 136; American Hospital Association, Annual Survey Database Fiscal Year 2008.

limited penetration in Africa, south-east Asia, and eastern Europe.⁹⁰ Consequently, many patients in a hospital setting do not receive appropriate palliative care, 'experience uncontrolled symptoms, and have limited opportunity to discuss goals of care'.⁹¹ In practice, there are many barriers which limit the development of hospital-based palliative care including the misperception of palliative care as relevant only to individuals at the end of life. Programmes such as Hospice Friendly Hospitals in Ireland have sought to address such limitations. Hospice Friendly Hospitals was launched in 2007 by the Irish Hospice Foundation. The programme focuses on ensuring that end-of-life care is central in hospital care, on bringing it from the periphery into the mainstream, and on altering the culture of end-of-life care in hospitals. At the time of writing, this programme continues to be in operation.

1.2.3 The community setting

The general practitioner and public health nurse have a central role in the provision of palliative care in the community setting.⁹² Other disciplines involved in the provision of palliative care in the community include physiotherapists, occupational therapists, social workers, specialist palliative care nurses, and speech and language therapists.⁹³ These professions may contribute in the form of a home palliative care team which provides support for community based palliative care. For instance, the EAPC have described the role of the home palliative care team as providing 'specialised palliative care to patients who need it at home and support to their families and carers at the patient's home. They also provide specialist advice to general practitioners, family doctors and nurses caring for the patient at home'.⁹⁴ These teams are not present in all countries. Consequently, care in the community setting may be 'delivered by specialist palliative nursing services and by specialist physicians working in general practice or in home-care support services'.⁹⁵ Locations where palliative care may be provided in the community include the patient's home, a community hospital, a nursing home, or any other community based setting.⁹⁶

The provision of palliative care in a community setting is increasingly important but it also faces significant challenges. Many of these challenges as well as the reasons underlying the importance of providing palliative care in this location have been touched on already in the introduction to this work and in this chapter. For

90 Ibid. 137.

91 Kelley (note 85) 143; A.M. Walling and others, 'The quality of care provided to hospitalized patients at the end of life' (2010) 170(12) *Archives of Internal Medicine* 1057.

92 Department of Health and Children (note 30) 86; S. Payne, 'To supplant, supplement or support? Organisational issues for hospices' (1998) 46(11) *Social Science and Medicine* 1495.

93 Department of Health and Children (note 30) 86.

94 European Association of Palliative Care (note 76) 29.

95 Ibid. 30.

96 Department of Health and Children (note 30) 34.

instance, among the realities of palliative care provision is the variation between a person's preferred place of death and the location where they actually die. The preference for a particular place of death has an important role in contributing to a 'good' death. This is linked to self-determination and patient autonomy.⁹⁷ It is necessary that such preferences be listened to and respected as far as possible. The legal framework should therefore not serve as an impediment to the delivery of appropriate palliative care.

Moreover, it was highlighted earlier in this chapter that there has been an expansion in the illnesses and aetiologies which palliative care is provided for. It is no longer limited to cancer patients who are terminally ill but is also beneficial for patients experiencing long-term chronic conditions such as chronic obstructive pulmonary disease. These patients can be cared for in the community setting due to their disease trajectory.⁹⁸ This is increasingly important as such care can reduce the burden which would instead be placed on hospitals and hospices.

Research suggests that cancer patients have a preference for dying at home.⁹⁹ Similarly, this preference has been demonstrated among different ethnic groups and across jurisdictions.¹⁰⁰ Nevertheless, a majority of people die in a hospital setting.¹⁰¹ The effect of this is that home deaths have decreased in many jurisdictions although research by Gomes et al. suggests a small reversal in the UK.¹⁰² A decrease in home deaths places an increased burden on the healthcare system and when coupled with population trends it underlines the challenge of providing appropriate palliative care into the future. It has previously been suggested that

97 S.T. Tang and C.H. Chen, 'Place of Death and Dying' in J. Cohen and L. Deliens, *A Public Health Perspective on End of Life Care* (Oxford University Press 2012) 21 'Achieving a patient's preferred place of death is a marker of all efforts to enable a "good" death, one in accordance with the wishes of the patient and their family, as suggested by the Institute of Medicine.'

98 L. Van den Block, 'Palliative Care in Primary Care' in J. Cohen and L. Deliens (eds) *A Public Health Perspective on End of Life Care* (Oxford University Press 2012) 120; L. Selman and others, 'Modelling services to meet the palliative care needs of chronic heart failure patients and their families: current practice in the UK' (2007) 21(5) *Palliative Medicine* 385.

99 Tang (note 97) 22; J. Nilsson and others, 'End-of-life care: Where do cancer patients want to die? A systematic review' (2017) *Asia-Pacific Journal of Clinical Oncology* [epub ahead of print]; E. Arnold and others, 'Preferred place of death for patients referred to a specialist palliative care service' (2015) 5(3) *BMJ Supportive & Palliative Care* 294; I.L. Higginson and G.J. Sen-Gupta, 'Place of care in advanced cancer: a qualitative systematic literature review of patient preferences' (2000) 3(3) *Journal of Palliative Medicine* 287.

100 J. Koffman and I.J. Higginson, 'Dying to be home? Preferred location of death of first-generation black Caribbean and native-born white patients in the United Kingdom' (2004) 7(5) *Journal of Palliative Medicine* 628.

101 Tang (note 97) 22 'Contemporary population-based studies indicate that the most common place of death around the world, for all causes of death, is hospital.'

102 Ibid. 23 'Furthermore, home deaths for cancer patients show decreasing trends in the UK, Italy, Greece, Korea, and Taiwan. Increasing trends for home deaths were reported in the US and Canada.'; B. Gomes and others, 'Reversal of the British trends in place of death: time series analysis 2004–2010.' (2012) 26(2) *Palliative Medicine* 102.

factors related to the place of death could act as ‘focal points for policies facilitating patients dying in their place of choice’.¹⁰³ There are a range of factors which influence the place of death.¹⁰⁴ These include ‘factors related to illness, personal attitudinal variables, social support, environmental factors, and macro-social factors (historical trends)’.¹⁰⁵ There are many considerations which inform these various factors and the interplay between them may not always be obvious. However, it can be suggested that a key point in achieving the preferred place of death is clear communication. In effect, the preference must be communicated by the patient. Research by Meeussen et al. illustrated that ‘GPs are often unaware of their patients’ preferences for place of death. However, if GPs are informed, patients often die at their preferred location.’¹⁰⁶ This is not to ignore the relevance of other factors but it highlights the importance of respecting patient autonomy in practice.

The impediments facing the provision of palliative care in a community setting echo the challenges which arise in hospice and hospital settings. Referral criteria needs to be clear for healthcare professionals so patients can move between the different levels of palliative care provision in an appropriate manner. This not only requires clear referral criteria but is significantly influenced by the knowledge and expertise of the healthcare professional. As such, it cannot be expected that general practitioners would have the same level of knowledge as professionals who regularly provide specialist palliative care. Cohen and Deliens set out that ‘since most GPs have only a few terminally ill patients they care for each year – albeit variable across countries and individual GPs – it cannot be expected that all GPs and nurses in regular home care are equipped to provide *specialist palliative care*’.¹⁰⁷ In addition to this, the categorisation of palliative medicine as a medical speciality underlines the difficulty facing general practitioners in keeping up to date with new practices and research. On this basis, the availability of assistance from specialist palliative care teams as a support for primary caregivers is an essential facet of delivering appropriate palliative care in the community setting.¹⁰⁸

The practice of providing palliative care in the community began shortly after the opening of St Christopher’s Hospice in 1967.¹⁰⁹ St Christopher’s Hospice established home care services in October 1969.¹¹⁰ The origins of home care

103 Tang (note 97) 24.

104 B. Gomes and I.J. Higginson, ‘Where people die (1974–2030): past trends, future projections and implications for care’ (2008) 22(1) *Palliative Medicine* 33.

105 Tang (note 97) 24.

106 K. Meeussen and others, ‘GPs’ awareness of patients’ preference for place of death’ 2009 59(566) *British Journal of General Practice* 665, 665.

107 Van den Block (note 98) 115 [emphasis in original]

108 Ibid. 120; European Association of Palliative Care (note 76) 24 ‘Now, as in the future, a major part of palliative care will be provided by nonspecialist services. Consequently, non-specialist professionals must have easy access to specialist consultation for advice and support.’

109 Baines (note 26).

110 M. Baines, ‘Pioneering days of palliative care’ (2011) 18(5) *European Journal of Palliative Care* 223.

services are closely linked to the experiences of a specific patient in the early days of the hospice movement. The patient wished to go home once her pain was being controlled. She returned home but adequate pain management was not continued by her general practitioner resulting in her returning to St Christopher's Hospice.¹¹¹ Consequently, St Christopher's began to develop home care services for such patients. These services were 'based on the needs of patients at home, after consultation with general practitioners and district nurses who were already working in the community'.¹¹² Dame Cicely Saunders encouraged the development of this service and set out that '[t]he hospice will provide continuity of care for those able to return home.'¹¹³ This service has continued to develop over the years and in 2010 'no less than 1,800 new patients were visited and 48% of deaths occurred at home'.¹¹⁴

Support for home care services is also provided by Marie Curie nurses. This is one of the core services offered by the Marie Curie charity and they have an integral role in maintaining home care.¹¹⁵ A similar service is offered in Ireland by the Irish Cancer Society. The Irish Cancer Society¹¹⁶ has been involved in the advancement of home-care nursing services since 1985.¹¹⁷ Services include 'Night Nursing' which provides 'end of life care for cancer patients and their families in their own home'.¹¹⁸ This care not only focuses on physical pain but also provides emotional care of the patient. In 2013, 1,868 patients availed of this service.¹¹⁹

Care at the end of life is also increasingly provided in long-term care settings such as nursing homes. Nursing home residents are likely to experience a chronic rather than an acute illness.¹²⁰ This would require elements of palliative care. In such situations, palliative care in the nursing home is generally provided by the patient's general practitioner with support provided by the nursing staff. The provision of specialist palliative care may involve 'consultation with the staff of

111 Ibid.

112 M. Baines, 'The origins and development of palliative care at home' (2010) 18(1) *Progress in Palliative Care* 4, 4.

113 C. Saunders, 'St Christopher's Hospice' (1967) 77(10) *Br Hosp J Soc Serv Rev* 2127 quoted in Baines (note 112) 4.

114 Baines (note 110).

115 I.J. Higginson and S. Wilkinson, 'Marie Curie nurses: enabling patients with cancer to die at home' (2002) 7(5) *British Journal of Community Nursing* 240.

116 L. O'Síoraín and others, 'The Voluntary Sector' in J. Ling and L. O'Síoraín (eds), *Palliative Care in Ireland* (Open University Press 2005) 26 'the major national cancer charity whose remit includes all cancer care from screening programmes to hospice home care.'

117 Department of Health and Children (note 30) 22; O'Síoraín (note 116) 26.

118 Irish Cancer Society, 'Home Night Nursing' <<http://www.cancer.ie/how-we-can-help/nursing/home-night-nursing>> accessed 8 May 2017.

119 Ibid.

120 J. van der Steen and others, 'Palliative Care in Institutional Long-term Care Settings' in J. Cohen and L. Deliens (eds) *A Public Health Perspective on End of Life Care* (Oxford University Press 2012) 122; S.C. Miller and toerhs, 'The growth of hospice care in U.S. nursing homes' (2010) 58(8) *Journal of the American Geriatric Society* 1481.

the specialist palliative care unit, or may involve visits to the nursing home by the specialist palliative care team in the community'.¹²¹ As such, the provision of specialist palliative care does not have a central role in nursing home care. However, '[n]ursing home residents generally have high care needs because admission to a long-term care facility is usually the result of cognitive and functional decline with progressive dependency on care that cannot be provided at home'.¹²² The nature of such decline also raises challenges in accurately identifying the patient's prognosis.¹²³ In turn, this makes it increasingly difficult to identify when a move to specialist palliative care is required.

Specialist palliative care has evolved from hospices to become a more central part of the healthcare system. It is a practice which is still developing as evidenced by the emergence of programmes such as Hospice Friendly Hospitals in Ireland and the growth in home care. Regardless of location, doctors and nurses are to the fore in providing specialist palliative care. In order to provide effective palliative care it is necessary that these professions share a common understanding of the nature of this type of care and are supported by a clear legal framework when providing specialist palliative care. In this regard, guidelines and standards must directly address the provision of specialist palliative care practices. Consequently, it is necessary to highlight the legal and ethical issues which healthcare professionals are confronted with when engaging in specialist palliative care practices.

1.3 Palliative care practices

There are a broad range of palliative care practices such as medication management,¹²⁴ prevention of bed sores,¹²⁵ and treating elimination problems experienced by patients.¹²⁶ These practices are relatively uncontroversial and raise few legal issues other than providing respect for patient autonomy and ensuring that the patient is treated with dignity. However, the specialist palliative care practices of palliative sedation and the decision to withhold or withdraw artificial nutrition and

121 Department of Health and Children (note 30) 90.

122 van der Steen (note 120) 123.

123 M.A. Brown and others, 'Prognostic indicators of 6-month mortality in elderly people with advanced dementia: A systematic review' (2013) 27(5) *Palliative Medicine* 389; H.E. Brandt and others, 'Symptoms, signs, problems, and diseases of terminally ill patients: a nationwide observational study in the Netherlands' (2005) 165(3) *Archives of Internal Medicine* 314.

124 H.M. Holmes and others, 'Reconsidering medication appropriateness for patients late in life' (2006) 166(6) *Archives of Internal Medicine* 605; D.C. Currow, 'Prescribing in palliative care as death approaches' (2007) 55(4) *Journal of the American Geriatrics Society* 590.

125 M. Walding and C. Andrews, 'Preventing and managing pressure sores in palliative care' (1995) 11(1) *Professional Nurse* 33; J. Galvin, 'An audit of pressure ulcer incidence in a palliative care setting' (2002) 8(5) *International Journal of Palliative Nursing* 214.

126 P.J. Larkin and others, 'The management of constipation in palliative care: clinical practice recommendations' (2008) 22(7) *Palliative Medicine* 796.

hydration are more challenging. This section will outline these practices and, in doing so, will illustrate the complicated decisions faced by the healthcare professional in providing specialist palliative care. In addition to this, it provides an introduction to many of the legal and ethical issues which will be discussed over the course of this work.

1.3.1 Sedation in palliative care

Sedation in palliative care has been described as a ‘contested practice’.¹²⁷ Seymour et al. summarised this situation in commenting that:

Contemporary debates focus on how its use relates to euthanasia, issues of informed or advance consent, its role in ‘death with dignity’ and its relationship to the withholding or withdrawing of life prolonging medical treatments, particularly artificial feeding and hydration.¹²⁸

The practice therefore attracts considerable legal and ethical concerns. This section will set out the background to several of these issues yet this quote does not reveal all the dimensions of sedation. There are challenges posed by the expansive taxonomy of sedation, clinical aspects of sedation, and indications and preconditions for the administration of sedation. This section will outline these elements and, in so doing, will highlight the complexity of the practice.

The use of sedation in palliative care developed due to the greater focus placed on pain management by palliative care providers as well as developments in the provision of medication.¹²⁹ Levels of sedation include mild sedation, respite sedation and deep sedation.¹³⁰ Mild sedation involves lowering the consciousness of the patient but the patient is awake. Respite sedation involves sedating the patient for ‘a predetermined interval, such as 24 to 48 hours, then downwardly titrating the sedative until consciousness reappears’.¹³¹ The benefit

127 J.E. Seymour and others, ‘Relieving suffering at the end of life: practitioners’ perspectives on palliative sedation from three European countries’ (2007) 64(8) *Social Science & Medicine* 1679, 1679.

128 Ibid. 1680; L. Deliens and others, ‘End-of-life decisions in medical practice in Flanders, Belgium: A nationwide survey’ (2000) 356 *The Lancet* 1806.

129 Improved accuracy of medication delivery e.g. use of intrathecal therapies which began to develop in 1976. T.L. Yaksh and T.A. Rudy, ‘Analgesia mediated by a direct spinal action of narcotics’ (1976) 192(4246) *Science* 1357; M.E. Leavens and others, ‘Intrathecal and intraventricular morphine for pain in cancer patients: initial study’ (1982) 56 *Journal of Neurosurgery* 241; B. Roquefeuil and others ‘Analgesia by intraventricular injection of morphine’ (1982) 23 *Agressologie* 119; S. Belverud and others, ‘Intrathecal pumps’ (2008) 5(1) *Neurotherapeutics* 114.

130 A. de Graeff and M. Dean, ‘Palliative sedation therapy in the last weeks in life: a literature review and recommendations for standards’ (2007) 10 *Journal of Palliative Medicine* 67, 73–74.

131 P.C. Rousseau, ‘Palliative sedation’ (2002) 19 *American Journal of Hospice Palliative Care* 295, 296.

of this form of sedation is that it may assist in easing the anxiety and distress experienced by the patient.¹³² However, it is the practice of deep sedation which is most controversial.¹³³ It is also a practice which is increasingly prevalent.

Miccinesi et al. examined the practice of continuous deep sedation in six European countries between June 2001 and February 2002.¹³⁴ This research demonstrated that continuous deep sedation was administered in 8.5% of deaths in Italy and in 8.2% of deaths in Belgium. A slightly lower prevalence was seen in Denmark and Sweden where the prevalence was 2.5% and 3.5% respectively. A rate of 4.8% was seen in Switzerland during this period. The prevalence of continuous deep sedation has increased beyond these figures in many countries. For instance in the UK, research conducted by Seale on end-of-life decisions between 2007 and 2008 suggested a frequency of 16.5% although study limitations may have led to an overestimation of prevalence.¹³⁵ More recent research has been conducted in Austria. Schur et al. examined the practice of sedation in Austria in the period June 2012 to June 2013.¹³⁶ It included 2414 patients, of whom 21% received sedation and, of these, 71% received continuous sedation until death. This represented 356 patients out of a sample size of 2414.¹³⁷ There have been repeated studies conducted in Flanders, Belgium, which provide greater insight into the development of the practice in that jurisdiction. For instance, in Flanders the rate of continuous deep sedation was 8.2% in 2001 and rose to 14.5% in 2007.¹³⁸ In contrast to this, it was shown in a repeated survey that the prevalence of continuous deep sedation had dropped to 12% in 2013. The research highlighted improvements in practice but also areas such as the decision-making process which could be improved. The high prevalence of sedation is clear but deeper cross-jurisdictional analysis is limited at this point by differences in research methodology, differences in terminology, or even the legal framework which exists in each jurisdiction.

Differences or confusion relating to the terminology is very possible given the range of terms which have been used to describe sedation. The profusion of terms

132 Ibid. 296. 'With respite sedation, an indeterminate number of patients may break the cycle of anxiety and distress that precipitated the request and need for palliative sedation, thereby nullifying the need for further sedation.'

133 T. Morita and others, 'Continuous deep sedation: a proposal for performing more rigorous empirical research' (2017) 53(1) *Journal of Pain and Symptom Management* 146.

134 G. Miccinesi and others, 'Continuous deep sedation: physicians' experiences in six European countries' (2006) 31(2) *Journal of Pain and Symptom Management* 122.

135 C. Seale, 'End-of-life decisions in the UK involving medical practitioners' (2009) 23 *Palliative Medicine* 198.

136 S. Schur and others, 'Sedation at the end of life – a nation-wide study in palliative care units in Austria' (2016) 15(50) *BMC Palliative Care*.

137 This represents an overall prevalence of 14.7%.

138 J. Bilsen and others, 'Medical end-of-life practices under the euthanasia law in Belgium' (2009) 361 *New England Journal of Medicine* 1119.

led ten Have and Welie to describe the situation as one of 'terminological polysemy'.¹³⁹ Terms include continuous sedation,¹⁴⁰ deep sedation,¹⁴¹ sedation for intractable distress in the dying,¹⁴² total pharmacological sedation,¹⁴³ sedation-induced sleep,¹⁴⁴ end of life sedation,¹⁴⁵ palliative sedation,¹⁴⁶ controlled sedation,¹⁴⁷ and terminal sedation.¹⁴⁸ This is not an exhaustive taxonomy and terms continue to be advanced. Moreover, these terms are not synonyms for the same practice but may refer to practices with different clinical indications, pharmacological differences, and varying ethical considerations. This issue is further compounded by the fact that the terms are not always used in a consistent manner. For instance, multiple definitions for many of these terms have been advanced. This resulting lack of clarity is illustrated by the term 'terminal sedation' which was among the first terms used to describe the practice of sedation at the end of life.

The term 'terminal sedation' was first proposed by Enck in 1991 and was one of the most commonly used terms to describe this level of sedation.¹⁴⁹ Even before considering differences in definition, there is a lack of clarity as to whether the word 'terminal' means that the patient is terminally ill or that the sedation is

- 139 H. ten Have and J.V.M. Welie, 'Palliative sedation versus euthanasia: an ethical assessment' (2014) 47(1) *Journal of Pain and Symptom Management* 123, 126.
- 140 K. Raus and others, 'Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide?' (2011) 11(6) *American Journal of Bioethics* 32.
- 141 N.I. Cherny, L. Radbruch and The Board of the European Association for Palliative Care, 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care' (2009) 23(7) *Palliative Medicine* 581.
- 142 S. Chater and others, 'Sedation for intractable distress in the dying – a survey of experts' (1998) 12 *Palliative Medicine* 255.
- 143 C. Peruselli and others, 'Home palliative care for terminal cancer patients: a survey on the final week of life' (1999) 13 *Palliative Medicine* 233.
- 144 V. Ventafridda and others, 'Symptom prevalence and control during cancer patients' last days of life' (1990) 6 *Journal of Palliative Care* 7.
- 145 C.J. Fürst and K. Hagenfeldt, 'End-of-life sedation: definition and clinical guidelines needed' (2002) 99(39) *Lakartidningen* 3830.
- 146 P. Claessens and others, 'Palliative sedation: a review of the research literature' (2008) 36(3) *Journal of Pain and Symptom Management* 310; P. Rousseau, 'Palliative sedation in the management of refractory symptoms' (2004) 2(2) *Journal of Supportive Oncology* 181.
- 147 B.R. Taylor and R.M. McCann, 'Controlled sedation for physical and existential suffering?' (2005) 8(1) *Journal of Palliative Medicine* 144.
- 148 R.E. Enck, 'Drug-induced terminal sedation for symptom control' (1991) 8 *American Journal of Hospice and Palliative Care* 2; J.D. Cowan and D. Walsh, 'Terminal sedation in palliative medicine – definition and review of the literature' (2001) 9 *Support Cancer Care* 403.
- 149 J.G. Hasselaar and others, 'When cancer symptoms cannot be controlled: the role of palliative sedation' (2009) 3 *Current Opinion in Supportive and Palliative Care* 14 cited in M. Maltoni, E. Scarpi and O. Nanni, 'Palliative sedation in end-of-life care' (2013) 25(4) *Current Opinion in Oncology* 360, 360 'Hasselaar et al. reported that in 1998–1999 all studies referred to the procedure as "terminal sedation", an inappropriate choice of words as it gives the impression of an intervention aimed at terminating life.'

aimed at allowing the patient to die.¹⁵⁰ Terminal sedation is therefore often viewed as being somewhat ethically dubious, as evidenced by the title of Torbjörn Tännsjö's book *Terminal Sedation: Euthanasia in Disguise?*¹⁵¹ More recently, the term 'palliative sedation' has received greater use in the relevant literature.¹⁵² However, this term has been criticised by Battin who views palliative sedation as a euphemism for terminal sedation.¹⁵³ In sum, the terminology used to describe sedation is especially important given the legally and ethically sensitive nature of specialist palliative care. It was suggested by Jackson that the 'words we use in medical discourse reveal much about our truest conceptions and (and subconscious assumptions) about the practice of the profession'.¹⁵⁴ In effect, the choice of a term, and the definition relied upon, can be interpreted as a value judgment which shapes the course of subsequent research and discussion. The term and definition used, would impact on the recorded prevalence of sedation and influence the application of ethical justifications such as the doctrine of double effect. As the incidence of sedation is closely tied to how broad or narrow a definition is this can result in considerable discrepancies in the recorded statistics and frustrates attempts at consistent analysis across institutions and jurisdictions.¹⁵⁵

In this work, the term 'palliative sedation' will be used throughout, although other terms may be used at times to accurately reflect the terminology used in research articles, book chapters, or reports. The term 'palliative sedation' emphasises the palliative element which is central to this work and has been widely used in

- 150 T. Morita and others, 'Definition of sedation for symptom relief: a systematic literature review and a proposal of operational criteria' (2002) 24(4) *Journal of Pain and Symptom Management* 447; D.A. Jones, 'Death by Equivocation: A Manifold Definition of Terminal Sedation' in S. Sterckx, K. Raus and F. Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013) 47, 50.
- 151 M.P. Battin, 'Terminal sedation: pulling the sheet over our eyes' (2008) 38(5) *Hastings Center Report* 27; T. Tännsjö, 'Terminal Sedation: A Substitute for Euthanasia' in T. Tännsjö (ed.), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004).
- 152 Maltoni (note 149) 360 'By 2006–2008, 83% of studies were using the term "palliative sedation"'.
- 153 Battin (note 151); M.Y. Rady and J.L. Verheijde, 'Continuous deep sedation until death: palliation or physician-assisted death?' (2010) 27(3) *American Journal of Hospice and Palliative Medicine* 205.
- 154 W.C. Jackson, 'Palliative sedation vs. terminal sedation: What's in a name?' (2002) 19 *American Journal of Hospice Palliative Care* 81, 82; S. Rys and others, 'Continuous sedation until death: moral justifications of physicians and nurses – a content analysis of opinion pieces' (2013) 16 *Medicine, Health Care and Philosophy* 533, 539 'The distribution of the terms "palliative" and "terminal" sedation throughout the various opinion pieces shows a struggle over the emotive meanings of the words used in discussing CSD. Terms such as "palliative" or "terminal" have different so-called (by Stevenson) emotive meanings.'
- 155 Rys (note 154) 539 'We can conclude that a clear (moral) debate on CSD is seriously hindered by the lack of uniform, neutral terms and definitions for CSD. Probably due to the controversial (and ambiguous) nature of CSD, the debate is profoundly marked by "charged language", rich in connotations, aiming at realizing agreement in attitude towards CSD.'

research papers, and is regularly used by professional palliative care organisations.¹⁵⁶ Palliative sedation is defined by the European Association for Palliative Care as:

the monitored use of medications intended to induce a state of decreased or absent awareness (unconsciousness) in order to relieve the burden of otherwise intractable suffering, in a manner that is ethically acceptable to the patient, family and health-care providers.¹⁵⁷

This definition highlights ethical concerns and indications for sedation along with the concept of intention. In many definitions of palliative sedation the practice is framed by this concept which can be problematic. Intention is inherently subjective and it will not always be clear what the intent of a physician was, particularly as the physician may act with more than one intention.¹⁵⁸ It has been suggested that as the physician may act with a partial intention to hasten the death of a patient then this practice gives rise to what could be considered a grey area.¹⁵⁹ In essence, questions surrounding the concept of intention may blur the boundary between palliative care and euthanasia. It has also been suggested that intention may 'depend on how one wants one's actions to be viewed'.¹⁶⁰

In order to assess the nature of the practice in a clearer manner it has been suggested by Bruinsma et al. and Van Delden that what is required is a descriptive definition which removes all normative elements.¹⁶¹ Van Delden advances the

156 Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2009); National Ethics Committee, Veterans Health Administration, 'The ethics of palliative sedation as a therapy of last resort' (2007) 23(6) *American Journal of Hospice and Palliative Medicine* 483; T.W. Kirk, M.M. Mahon and Palliative Sedation Task Force of the National Hospice and Palliative Care Organization Ethics Committee, 'National Hospice and Palliative Care Organization (NHPCO) position statement and commentary on the use of palliative sedation in imminently dying terminally ill patients' (2010) 39(5) *Journal of Pain and Symptom Management* 914; Cherny (note 141).

157 Cherny (note 141) 581; S. Gevers, 'Terminal sedation: a new legal approach' (2003) 10 *European Journal of Health Law* 359, 360 'the administration of sedative drugs with the aim to reduce the consciousness of a terminal patient in order to relieve distress'; Maltoni (note 149) 360 'Palliative sedation is a medical procedure used to deal with the refractory symptoms occurring in the advanced stages of cancer. It has clinical, nursing, relational and ethical implications, making it a highly sensitive issue.'

158 B.D. Onwuteaka-Philipsen and others, 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey' (2012) 380(9845) *Lancet* 908; J.A. Rietjens and others, 'Approaches to suffering at the end of life: the use of sedation in the USA and Netherlands' (2014) 40(4) *Journal of Medical Ethics* 235.

159 E. Papavasiliou and others, 'Current debates on end-of-life sedation: an international expert elicitation study' (2014) 22(8) *Support Care Cancer* 2141.

160 S.M. Bruinsma and others, 'Continuous sedation until death: state of the art' in S. Sterckx, K. Raus and F. Mortier (eds) *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013) 29, 39.

161 Ibid. 31; J.J. van Delden 'Terminal sedation: source of a restless ethical debate' (2007) 33(4) *Journal of Medical Ethics* 187.

definition that ‘continuous sedation is sedation until death follows’.¹⁶² This is helpful in isolating the core aspect of the practice but does little to illustrate the nuances of practice which must be accounted for in an assessment of the legal and ethical permissibility of palliative sedation. In this regard, the manifold definition proposed by Jones can prove helpful. Jones identified 17 independent elements as part of a manifold definition. These elements include the level of sedation, the severity of refractory symptoms, the presence of existential distress, the patient’s prognosis, a request for sedation, decisions about nutrition and hydration, and whether there is an intention to hasten death.¹⁶³ These elements highlight distinct issues which arise in the context of palliative sedation. As Jones noted, ‘[d]ifferent permutations of the manifold definition call attention to different ethical issues.’¹⁶⁴ In this respect, Jones also advances two distinct versions of the definition, namely strong terminal sedation and weak terminal sedation. However, a spectrum of practices exist between strong and weak terminal sedation.¹⁶⁵ It is this intervening space which gives rise to some of the most challenging and contentious uses of sedation due to the combination of intention, withdrawal or withholding of artificial nutrition and hydration, and the identification of what constitutes a refractory symptom.¹⁶⁶

Refractory symptoms

The main indication for palliative sedation is the presence of a ‘refractory symptom’ which is a ‘symptom for which all possible treatment has failed or it is estimated that no methods are available for palliation within the time frame and the risk–benefit ratio’¹⁶⁷ that is tolerable to the patient. This definition is silent on the cause of the symptom and, as a result, mental and emotional symptoms may be captured by this definition. Moreover, the reference to tolerability highlights a subjective influence.¹⁶⁸ On this basis, ‘[a] symptom that is intractable in one place, or when experienced by one person, may not be intractable if it occurs in another place or another individual.’¹⁶⁹

162 van Delden (note 161) 187.

163 Jones (note 150) 59.

164 Ibid. 64.

165 Ibid. 62.

166 V. Cellarius, ‘“Early terminal sedation” is a distinct entity’ (2011) 25(1) *Bioethics* 46. Terminal sedation as a distinct ‘third way’ between euthanasia and palliative care.

167 Maltoni (note 149) 362; A. Simon and others, ‘Attitudes towards terminal sedation: an empirical survey among experts in the field of medical ethics’ (2007) 6 *BMC Palliative Care* 1472 ‘98% of the respondents regarded terminal sedation in dying patients with treatment-refractory physical symptoms as acceptable.’

168 ten Have (note 139) 129.

169 N.P. Sykes, ‘Clinical aspects of palliative sedation’ in S. Sterckx, K. Raus and F. Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013) 86, 88.

Sedation may be administered for differing forms of distress such as delirium,¹⁷⁰ dyspnoea,¹⁷¹ pain,¹⁷² nausea,¹⁷³ existential distress,¹⁷⁴ restlessness,¹⁷⁵ and vomiting.¹⁷⁶ Existential distress is the emotional or mental distress experienced by the patient.¹⁷⁷ The administration of palliative sedation for suffering such as existential distress and restlessness alone is controversial¹⁷⁸ as it involves treating psychological distress rather than physical pain experienced by the patient. In this respect, existential distress may occur earlier in the disease trajectory at a time when the patient is not experiencing physical refractory symptoms.¹⁷⁹ Consequently, if palliative sedation is administered for existential distress alone then this would blur the purpose of palliative sedation as well as blurring the time at which palliative sedation can legitimately be provided. For example, the administration of palliative sedation to a physically healthy person who happens to be experiencing existential distress could not be considered an aspect of specialist palliative care. Instead it may be viewed as a practice more closely aligned with euthanasia. Nonetheless, a person experiencing existential distress alone near the end of life may benefit from lower forms of sedation such as respite sedation and should receive an appropriate level of palliative care.¹⁸⁰ The appropriate treatment of mental anguish is an important aspect of care but requires more than a pharmacological response. The need to appropriately respond to total pain was recognised from the early days of palliative care. Existential distress requires psychological care of the patient. This requires assessment by a healthcare professional with specialist knowledge of mental health.¹⁸¹ There are arguments that palliative sedation should be available

170 N.I. Cherny, 'Sedation in response to refractory existential distress: Walking the fine line' (1998) 16 *Journal of Pain Symptom Management* 404; Cowan (note 148) 406.

171 A. Beel and others, 'Palliative sedation therapy: a review of definitions and usage' (2002) 8(4) *International Journal of Palliative Nursing* 190, 193.

172 Ibid; Bruinsma (note 160) 36.

173 Maltoni (note 149) 362 'The symptoms most frequently requiring palliative sedation are physical symptoms such as delirium and dyspnea, whereas pain and vomiting are less frequently involved.'

174 Beel (note 171).

175 Ibid.

176 Ibid.

177 A. Bruce and P. Boston, 'Relieving existential suffering through palliative sedation: discussion of an uneasy practice' (2011) 67(12) *Journal of Advanced Nursing* 2732. This paper suggests that there is a lack of consensus surrounding the meaning of existential suffering.

178 T. Morita and others, 'Terminal sedation for existential distress' (2000) 17 *American Journal of Hospice Palliative Care* 189; P.C. Rousseau, 'Existential suffering and palliative sedation: A brief commentary with a proposal for clinical guidelines' (2001) 18 *American Journal of Hospice Palliative Care* 151; T. Morita, 'Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients' (2004) 28 *Journal of Pain Symptom Management* 445; Taylor (note 147).

179 Simon (note 167)..

180 Irish Association of Palliative Care, 'Palliative Sedation' (March 2011); Cherny (note 141).

181 E. Delbeke, 'The legal permissibility of continuous deep sedation at the end of life: a comparison of laws and a proposal' in S. Sterckx, K. Raus and F. Mortier (eds),

for existential distress as well as suggestions that sedation may be used to ‘cover up a care team’s therapeutic shortcomings’.¹⁸² In an examination of the literature in this area de Graeff suggests that sedation for ‘psychological or existential distress should be initiated only under exceptional circumstances and only after consultations with experts in this area’.¹⁸³ The approach to existential distress in different jurisdictions will be considered in subsequent chapters.

Drugs used for sedation

Benzodiazepines, opioids and barbiturates are commonly used forms of palliative drugs.¹⁸⁴ An opiate such as morphine functions primarily as a painkiller, whereas benzodiazepines serve to sedate the patient so they do not feel the same level of pain. Opiates therefore are ‘not reliable sleep-inducing agents by themselves’.¹⁸⁵ In this regard it has been noted that ‘[a]lthough opioids are mentioned in the majority of studies, their use as the single sedating drug is not now recommended’.¹⁸⁶ Consequently, benzodiazepines or barbiturates¹⁸⁷ are increasingly used for palliative sedation, particularly midazolam.¹⁸⁸ Strong opioids used in palliative care include oxycodone, fentanyl, morphine, and hydromorphone. Morphine is the drug of choice for pain management when the pain is moderate to severe.¹⁸⁹ Fears about addiction, respiratory depression, and excessive sedation have been shown to be largely unfounded.¹⁹⁰ The use of opioids in palliative care

Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives (Cambridge University Press 2013) 132, 139 ‘Psychological suffering will inevitably need to be assessed more strictly than physical suffering. The refractory nature of the psychological suffering should at least be repeatedly assessed by a physician specialised in mental health care and with sufficient expertise.’

182 Sykes (note 169) 98.

183 de Graeff (note 130) 71; Rousseau (note 131) 295 This form of suffering ‘can be just as consequential and distressful as refractory physical symptoms.’; Bruce (note 177); Morita (note 178).

184 C. Selva, ‘International control of opioids for medical use’ (1997) 4(6) *European Journal of Palliative Care* 194, 194 ‘Opioids are mainly used for analgesia – acute or severe pain (eg, morphine, pethidine), mild to moderate pain (eg, codeine, dextro propoxyphene)’.

185 E.L. Krakauer and T.E. Quinn, ‘Sedation in Palliative Medicine’ in G. Hanks and others, (eds), *Oxford Textbook of Palliative Medicine* (4th edn, Oxford University Press 2011) 1566.

186 J. Porta-Sales, ‘Palliative sedation: clinical, pharmacological and practical aspects’ in S. Sterckx, K. Raus and F. Mortier (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013) 65, 69. See R.P. Reuzel and others, ‘Inappropriateness of using opioids for end-stage palliative sedation: a Dutch study’ (2008) 22(5) *Palliative Medicine* 641.

187 Rousseau (note 131) 185; Porta-Sales (note 186) 69.

188 Porta-Sales (note 186) 69; Claessens (note 146).

189 P. Klepstad and others, ‘Pain and pain treatments in European palliative care units. A cross sectional survey from the European Association for Palliative Care Research Network’ (2005) 19 *Palliative Medicine* 477, 479.

190 H. McQuay, ‘Opioids in pain management’ (1999) 353 *Lancet* 2229.

has been recommended by the World Health Organisation. For example, the early work of the World Health Organisation on this topic emphasised the importance of opioid products being available for pain management.¹⁹¹

Palliative medication may be administered in a number of different ways including injection, oral, suppository or through intrathecal pump. The intrathecal pump functions by delivering 'small doses of medication directly to the spinal fluid'.¹⁹² This has the effect of increasing the 'relative strength of the drug compared to its oral or intravenous equivalent'.¹⁹³ This approach can minimise potential side effects of sedative drugs. The control exercised over the administration of sedative drugs is important due to the harmful consequences associated with an excessive dose. Naturally, it follows that sedation should be the 'lowest necessary to provide adequate relief of suffering'.¹⁹⁴ In the context of morphine it appears that when it is administered at such a level there is 'little data to support the belief that appropriate use of opioids hastens death in patients dying from cancer and other chronic diseases'.¹⁹⁵ The challenge which this presents is the identification of what constitutes an appropriate level of sedative. This level will vary over the course of a patient's care, for example, after the initial sedation the risk of hastening death decreases. This is based on the fact that the 'risk of respiratory depression is greatest when opioids are first begun'.¹⁹⁶ As treatment progresses, the ability of a patient to cope with respiratory side effects increases,¹⁹⁷ but over time toxicity may occur.

191 World Health Organization, *Cancer Pain Relief: With a Guide to Opioid Availability* (2nd edn, World Health Organization 1996) 50.

192 Belverud (note 129).

193 Ibid.

194 Cherny (note 141) 586; de Graeff (note 130) 67 'The initial dose of sedatives should usually be small enough to maintain the patients' ability to communicate periodically.'; Rousseau (note 178) 153 'Finally, once PS is initiated, the dosage of the sedative agent should not be increased unless the patient awakens, is restless or grimaces, withdraws from touch and other stimuli, or has any other findings that could reasonably be interpreted as evidence of suffering, including tachypnea or tachycardia.'

195 S. Anderson Fohr, 'The double effect of pain medication: separating myth from reality' (1998) 1(4) *Journal of Palliative Medicine* 315, 318; N. Sykes and A. Thorns, 'The use of opioids and sedatives at the end of life' (2003) 4 *The Lancet Oncology* 312, 312 'there is no evidence that initiation of treatment, or increases in dose of opioids or sedatives, is associated with precipitation of death'.; de Graeff (note 130) 77 'Retrospective studies strongly suggest that appropriately used PST does not shorten life.'; R. Huxtable, *Euthanasia, Ethics and the Law: From Conflict to Compromise* (Routledge-Cavendish 2007) 88–91; J. Legemaate and others, 'Palliative sedation in the Netherlands: starting-points and contents of a national guideline' (2007) 14 *European Journal of Health Law* 61, 64 'The committee has taken the view that palliative sedation is a normal medical procedure and must be clearly distinguished from termination of life, because there is no evidence that palliative sedation – if administered carefully – hastens death.'

196 Anderson Fohr (note 195) 316 citing C.S. Hill, 'The barriers to adequate pain management with opioid analgesics' (1993) 20 *Seminars in Oncology* 1. Note that opioids are used far less frequently.

197 A. Alpers, 'Criminal act or palliative care? Prosecutions involving the care of the dying' (1998) 26 *Journal of Law, Medicine and Ethics* 308, 310 'Significant respiratory

The level of sedation which results in toxicity varies among people.¹⁹⁸ Toxicity depends on factors such as 'the degree of responsiveness of the pain to opioid, prior exposure to opioids, rate of titration of the dose, concomitant medication, and renal function'.¹⁹⁹ Similarly, patients may often develop a tolerance to benzodiazepines over the course of sedation.²⁰⁰ This should be factored in when commencing palliative sedation through the use of a benzodiazepine.²⁰¹ The combination of these factors underlines the difficulty in accurately judging an appropriate level of the sedative drug. A patient experiencing toxicity may demonstrate agitation which could be seen as pain which is not being adequately controlled.²⁰² In this regard, 'benzodiazepines can precipitate and worsen a pre-existing delirium'.²⁰³ For instance, 'a delirium worsened by benzodiazepines in a dying patient can be mistaken for "normal" or "expected" agitation and masked with a subsequent rapid increase of the benzodiazepine dose until the patient becomes comatose or dies'.²⁰⁴ Consequently, in demonstrating these symptoms further sedation may be given to control the presumed pain.²⁰⁵ This has been described as a 'vicious cycle'²⁰⁶ and results in even greater toxicity.²⁰⁷ The potential effect of this is that an excessive dose may be administered.

There is considerable support for the argument that opioids and sedatives do not hasten the death of the patient. For example, Sykes and Thorns determined that 'there is no evidence that initiation of treatment, or increases in dose of opioids or sedatives, is associated with precipitation of death'.²⁰⁸ Furthermore, Sykes and Thorns concluded that '[s]edation is generally used over a short period and most of the evidence suggests that in the context of specialist palliative care it

depression rarely occurs in a patient whose opioid dose has been gradually adjusted against pain.'; Anderson Fohr (note 195) 316.

198 B. O'Neill and M. Fallon, 'ABC of palliative care: principles of palliative care and pain control' (1997) 315(7111) *British Medical Journal* 801, 804.

199 Ibid.

200 Porta-Sales (note 186) 69–71 'It is important to be aware that all benzodiazepines induce tolerance after a couple of weeks of administration, and in the case of patients with far-advanced diseases it is not uncommon to use benzodiazepines for longer periods. This should be taken into account when considering the starting doses of benzodiazepines for palliative sedation, since the effect of the benzodiazepines is dose-dependent.'

201 Ibid. 70–71; H. Kuhse, *The Sanctity-of-Life Doctrine in Medicine: A Critique* (Clarendon Press 1987) 87 constant monitoring of the level of palliative medication administered is essential in avoiding what Kuhse describes as 'pyramid' pain-killing i.e. 'the administration of increasing and finally lethal doses of pain-killing drugs'.

202 O'Neill (note 198) 804.

203 Porta-Sales (note 186) 76; See W. Breitbart and others, 'A double-blind trial of haloperidol, chlorpromazine, and lorazepam in the treatment of delirium in hospitalized AIDS patients' (1996) 153(2) *American Journal of Psychiatry* 231.

204 Porta-Sales (note 186) 71.

205 O'Neill (note 198) 804.

206 Ibid.

207 Ibid.

208 Sykes (note 195), 312

is not associated with shortening of life.²⁰⁹ This research drew on 17 studies which examined sedative use for cancer patients who were nearing the end of life.²¹⁰ It also included a systematic review which examined three studies published in Spanish. These studies were retrospective and prospective. They included sedation administered in the home, as part of hospital care, in palliative care units, and in a combination of these locations. These studies reflect the various ways and locations in which specialist palliative care practices may be provided. Research published in 2009 by Maltoni et al. also serves to underline the fact that appropriate use of palliative sedation does not hasten the death of the patient.²¹¹ This point was again demonstrated by a subsequent literature review conducted by Maltoni et al.²¹² The cumulative effect of these studies is to demonstrate that the primary purpose of administering opioids and sedatives is that of pain relief, and this is not achieved through hastening the death of the patient. As noted by Sykes, '[p]roperly understood, the clinical purpose of sedative drugs in palliation is the reduction of irritability or agitation, i.e. the relief of distress.'²¹³

It has been mentioned by some that palliative care needs to 'accept that there are some occasions when the process of death is hastened, either unknowingly or knowingly'.²¹⁴ This has led to suggestions that palliative sedation may amount to 'slow euthanasia'²¹⁵ or 'backdoor euthanasia'.²¹⁶ Mason and Laurie describe the practice as 'euthanasia hiding under the emollient terminology which can do little other than still further confuse the taxonomy of assisted dying'.²¹⁷ Such suggestions have resulted in an increased focus on the manner in which palliative

209 Ibid. 317.

210 Ibid. 314.

211 M. Maltoni and others, 'Palliative sedation therapy does not hasten death: results from a prospective multicenter study' (2009) 20 *Annals of Oncology* 1163.

212 Maltoni (note 149) 360 'Over the last 12 months, a number of authors have published interesting new findings on different areas of palliative sedation, that is prevalence, indications, monitoring, duration and choice of drugs. In particular, a clear definition of palliative sedation and of its more pronounced form, deep continuous sedation (DCS), has emerged. It has been confirmed that, when performed in the correct way and with the right aims, palliative sedation does not have a detrimental impact on survival.'

213 Sykes (note 169) 94.

214 M. Ashby, 'Death Causation in Palliative Medicine' in I. Freckelton and D. Mendelson (eds), *Causation in Law and Medicine* (Hampshire 2002) 228, 247; See also Gevers (note 157).

215 J.A. Billings and S.D. Block, 'Slow euthanasia' (1996) 12 *Journal of Palliative Care* 21; B.M. Mount, 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes' (1996) 12 *Journal of Palliative Care* 31; H. Brody, 'Commentary on Billings and Block's "Slow Euthanasia"' (1996) 12 *Journal of Palliative Care* 38; R.K. Portenoy, 'Morphine infusions at the end of life: the pitfalls in reasoning from anecdote' (1996) 12 *Journal of Palliative Care* 44.

216 Gevers (note 157) 360; Select Committee on Dying with Dignity (Québec, March 2012) 38 'For some physicians, continuous palliative sedation is very different from euthanasia. For others, it is simply euthanasia in disguise.'

217 J. Kenyon Mason and G.T. Laurie, *Mason & McCall Smith's Law & Medical Ethics* (9th edn, Oxford University Press 2013) 615.

sedation is used,²¹⁸ and a need to accurately distinguish this practice from euthanasia. Consequently, it is vital that the legality of palliative sedation be demonstrated. However, any dividing line would be viewed as illusory if there is an inadequate legal framework to support this distinction.

The practice of palliative care has moved from the margins to now occupying a more central role in healthcare systems. This is underlined by the prevalence of practices such as palliative sedation. However, it is important to remain aware of the origins and motivating factors behind the development of palliative care. The use of palliative sedation should be openly discussed and decisions made in a clear and transparent manner. This is not only relevant for the legal status of the practice but also for guarding against a culture of silence in the care of those at the end-of-life. A silence which the likes of Elizabeth Kübler-Ross and Cicely Saunders sought to break.²¹⁹ Furthermore, the terminology used to describe sedation illustrates the competing viewpoints which exist in this domain. Language therefore has an important role in shaping normative conceptions of care and defining the sphere of moral debate. Nevertheless, central to any such debate must be the care of the person. While the next chapter will consider the legal and ethical justifications for specialist palliative care practices it will also be important to reflect on the role of human rights in end-of-life care. This includes the right of autonomy; the importance of which is further illustrated by treatment withdrawal decisions.

1.3.2 *Artificial nutrition and hydration*

The withdrawal of artificial nutrition and hydration often accompanies palliative sedation but it is necessary to distinguish the two as they are ‘separate decisions supported by different legal and ethical principles’.²²⁰ Artificial nutrition involves the provision of nutrition through non oral methods such as nasogastric tube, percutaneous endoscopic gastrostomy tube, or the use of total parenteral nutrition.²²¹ Artificial hydration refers to:

218 B. Gordijn and R. Janssens, ‘Euthanasia and palliative care in the Netherlands: an analysis of the latest developments’ (2004) 12(3) *Health Care Analysis* 195, 204 ‘The issue of terminal sedation has only recently attracted public attention in the Netherlands, whereas it has been more extensively under debate abroad.’

219 Kübler-Ross (note 18); ten Have (note 139) 132. ‘care for dying patients as an intersubjective process, a shared journey that requires that we listen attentively to the patient’; C. Saunders, *Watch With Me: Inspiration for a Life in Hospice Care* (Mortal Press, 2003).

220 Gevers (note 157) 364; R.J. Dunlop and others, ‘On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?: A reply’ (1995) 21 *Journal of Medical Ethics* 141 cited in G.M. Craig, ‘On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues’ (1996) 22(3) *Journal of Medical Ethics* 147; *Fleming v Ireland & Ors* [2013] IEHC 2 [37]; Maltoni (note 149) 365 ‘The decision-making processes to start palliative sedation and to stop nutrition and hydration are actually two different processes.’

221 D.P. Sulmasy, ‘The Ethics of Medically Assisted Nutrition and Hydration at the End of Life’ in S.J. Youngner and R.M. Arnold, (eds) *The Oxford Handbook of Ethics at the End of Life* (Oxford University Press 2016) 126. See also surgical gastrostomy or

the administration of fluids to patients who are unable to tolerate oral fluids by any of the following routes: intravenous, subcutaneous, nasogastric, gastrostomy or jejunostomy. A distinction is generally made between such 'artificial' means and ordinary means, as in the use of a cup or spoon to administer fluids orally to a patient.²²²

Reasons given for withdrawing artificial nutrition and hydration include the suggestion that its provision would 'lengthen the dying process',²²³ it may be judged that the patient 'has nothing to gain from it',²²⁴ or the patient may have requested that artificial nutrition and hydration be stopped. It has been suggested that withdrawing hydration may be beneficial as it results in a reduction in coughing, vomiting, and interventions such as suctioning.²²⁵ However, such positions are to be questioned, particularly in light of a 2008 and 2014 Cochrane Review,²²⁶ and a 2011 literature review carried out by Raijmakers et al.²²⁷ which are discussed in turn below.

The purpose of the Cochrane Review was to examine the impact of artificial hydration on the 'quality and length of life'²²⁸ of patients receiving palliative care. This review identified five relevant studies. Three of these studies identified no 'significant differences in outcome'²²⁹ between patients who had received hydration and those who had not. Another study examined in the review 'found that sedation and myoclonus (involuntary contractions of muscles) were improved'²³⁰ in the group which had artificial hydration withdrawn. The final study showed that 'some fluid retention symptoms were significantly higher in the hydration group'.²³¹ A subsequent literature review was published in 2014. In the intervening time, there was one new study published. This study did not show a significant benefit stemming from assisted hydration in palliative care patients. The conclusion of both the 2008 and 2014 Cochrane Reviews was that 'there are insufficient good-quality studies to inform definitive recommendations for practice with

jejunostomy tube feeding, proctoclysis, intravenous hydration and nutrition, total parenteral nutrition, hypodermoclysis.

222 Irish Association of Palliative Care (note 46).

223 Gevers (note 157) 361.

224 Ibid.

225 de Graeff (note 130) 76.

226 P. Good and others, 'Medically Assisted Hydration for Adult Palliative Care Patients' (2008) 2 Cochrane Database of Systematic Reviews; Phillip Good and others, 'Medically Assisted Hydration for Adult Palliative Care Patients' (2014) 4 Cochrane Database of Systematic Reviews.

227 N.J.H. Raijmakers and others, 'Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects' (2011) 22 *Annals of Oncology* 1478.

228 Good (note 226).

229 Ibid. 1–2.

230 Ibid. 1.

231 Ibid.

regard to the use of medically assisted hydration in palliative care patients'.²³² The lack of a definitive position may be due in part to a paucity of randomised control trials in this area particularly due to the ethical challenges posed by such research.

A literature review has also been carried out by Raijmakers et al. which focussed on the provision of artificial hydration as well as artificial nutrition. Two of the papers in this literature review identified positive effects stemming from the provision of artificial hydration²³³ while two recognised negative effects.²³⁴ In contrast to this, four papers did not identify any effect on 'terminal delirium, thirst, chronic nausea, and fluid overload'.²³⁵ This literature review concludes that 'little is known concerning the life-shortening or prolonging effect'²³⁶ of artificial nutrition or artificial hydration. In effect, the position of existing research is such that it makes it difficult to establish appropriate guidelines for practice and makes court decisions on these practices more challenging.

The practice of artificial nutrition and hydration gives rise to a number of other issues which will be addressed in Chapter 2. These include broader debates about whether it is a form of medical treatment or care, the nature of the patient's prognosis, the role of patient autonomy, and the nature of the relationship between artificial nutrition and hydration and palliative sedation. The relationship between the two practices is complex and the decision-making framework for these practices can significantly impact on legal and ethical justifications in this area.

1.4 Conclusion

The aim of this chapter was to introduce the practice of palliative care and draw out the issues which would be addressed over the course of this work. The expansion in palliative care providers, the breadth of illnesses which palliative care responds to, and the challenges presented by specialist palliative care practices were outlined. Several key points emerged over the three sections. First, the limited state involvement in the early development of palliative care in the United Kingdom and Ireland was underlined. Representative bodies and non-governmental organisations have taken on much of the responsibility for developing what is now a recognised medical specialty. This also demonstrates that palliative care continues to evolve over time. The development of this form of care has consequences for social attitudes on death and dying, broader end-of-life practices, and the debates

232 P. Good and others, 'Medically assisted hydration to assist palliative care patients' <http://www.cochrane.org/CD006273/SYMPT_medically-assisted-hydration-to-assist-palliative-care-patients> accessed 21 May 2017; Good (note 226) 2 'There are insufficient good quality studies to make any recommendations for practice with regard to the use of medically assisted hydration in palliative care patients.'

233 Raijmakers (note 227) 1478 Positive effects were 'less chronic nausea, less physical dehydration signs'.

234 Ibid. 1478 Negative effects were 'more ascites, more intestinal drainage'.

235 Ibid.

236 Ibid. 1485.

about the limits of law at the end of life. Second, the value of a clear legal framework was especially clear in the second and third sections of this chapter owing to the variation in places of care and the legally and ethically challenging aspects of specialist palliative care. A clear legal framework serves to support and protect both the healthcare professional and the patient who is in an especially vulnerable condition. This is closely tied to the third point, namely that the legitimacy of the distinction between specialist palliative care practices and euthanasia must be examined. This clarifies the legality of specialist palliative care practices and will also expose the strengths and weaknesses in the existing legal framework.

2 Specialist palliative care and euthanasia

A legitimate distinction?

2.0 Introduction

The term ‘palliative’ comes from the Latin word ‘pallium’ which means ‘mask’ or ‘cloak’.¹ It was suggested by the Council of Europe that this demonstrates the true role of palliative care which is to hide ‘the effects of incurable disease, or providing a cloak for those who are left in the cold, because they cannot be helped by curative medicine.’² However, it has been advanced that there is another way in which palliative care may serve as a cloak. Suggestions have, for example, been made that certain palliative practices are a form of ‘slow euthanasia’³ and that ‘palliative care is an alternative to permitting euthanasia on grounds of compassion.’⁴ These comments indicate that specialist palliative care practices are not easily distinguished from forms of euthanasia. Confusion over this distinction has the potential to hamper the care offered to patients if healthcare professionals do not have clarity on the legal boundaries of care and treatment. The aim of this chapter is to examine the legitimacy of the distinction between specialist palliative care practices and euthanasia. It will be argued that a distinction can be made but the basis for this distinction is often precarious and influenced by subjective interpretation.

The legal status of specialist palliative care practices will be drawn out over the course of three sections. The starting point will not be the legal and ethical justifications which illustrate the points of divergence. Instead, the starting point must look to identify where the points of convergence lie. As palliative sedation has been equated with euthanasia it is necessary to highlight the source of such criticism. It is only through highlighting the points of similarity that the legal and

1 J.R.V. Marchant and J.F. Charles, *Cassell's Latin Dictionary (Latin-English and English-Latin)* (Cassell and Company 1948) [pallium] 390; W. Smith and J. Lockwood, *Chambers Murray Latin-English Dictionary* (Chambers 1976) [pallium] 504.

2 Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003 Explanatory Memorandum [43].

3 J.A. Billings and S.D. Block, ‘Slow euthanasia’ (1996) 12 *Journal of Palliative Care* 21.

4 J. Gilbert, ‘Palliative medicine: a new specialty changes an old debate’ (1996) 52(2) *British Medical Bulletin* 296, 297.

ethical justifications can be applied in a way which accurately addresses criticism. To ignore this would risk talking at cross purposes. On this basis, the practice of euthanasia in the Netherlands will be outlined in the first section. An examination of the Dutch system, as it operates in practice, provides greater insight into the practice of voluntary active euthanasia and physician assisted suicide than can be achieved from merely setting out the definition for these practices in a vacuum.⁵ In contrast to the Dutch system, if a doctor in England and Wales or Ireland provides voluntary active euthanasia it is likely to lead to a charge of murder or manslaughter. As a result, it is necessary to set out the law on murder and intention in these jurisdictions. The interpretation of intention is significant due to the challenges it poses for specialist palliative care and its centrality to the doctrine of double effect.

The third section of this chapter examines legal and ethical justifications for specialist palliative care practices including proportionality, patient autonomy, double effect, and the acts and omissions distinction. The doctrine has a significant role in distinguishing between specialist palliative care practices and euthanasia due to the distinction between intended and unintended but foreseen events. The doctrine will be applied to the practice of palliative sedation and this will illustrate that while the doctrine can provide a justification the reality is such that it is now more of a hindrance. Changes in sedative drugs and other developments in palliative medicine mean that reference to double effect raises connotations which do not necessarily reflect medical practice. Palliative sedation is often accompanied by the withdrawal of artificial nutrition and hydration (ANH) but they are distinct practices and are supported by separate justifications. The third section will therefore examine the application of the acts and omissions distinction in the context of specialist palliative care.

2.1 Euthanasia: law and practice in the Netherlands

The introduction of legislation for voluntary active euthanasia and physician assisted suicide in the Netherlands was motivated by several cases which came before the Dutch courts. In 1973, a doctor was prosecuted for administering a fatal dose of morphine to her mother.⁶ The woman was ‘partially paralyzed on one side, was incontinent, scarcely able to read any longer, and very hard of hearing.’⁷ As a result of this, she repeatedly expressed a wish to die. The court held the doctor to be guilty of taking the life of a patient by request but the doctor was merely given a suspended sentence of one week in prison.

5 Voluntary active euthanasia can be performed, subject to certain criteria, in jurisdictions including Belgium and Luxembourg; The Belgian Act on Euthanasia of May, 28th 2002; Loi du 16 mars 2009 sur l’euthanasie et l’assistance au suicide.

6 *Nederlandse Jurisprudentie* 1973, no. 183, District Court of Leeuwarden, 21, February 21, 1973; W. Lagerway (tr), ‘Euthanasia Case Leeuwarden – 1973’ (1988) 3 *Issues in Law and Medicine* 439.

7 Lagerway (note 6) 441.

Subsequent cases such as *Schoonheim*,⁸ *Chabot*,⁹ and *Brongersma*¹⁰ developed the reasoning to a point where a doctor could act in a direct way subject to certain criteria. The situation was described by Gevers as '[a] delicate balance ... between statutory law that prohibits euthanasia, case law that stipulates conditions for non-prosecution, and controlled acceptance in practice.'¹¹ Eventually the reasoning in these cases was put on a legislative footing by the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.

The 2001 Act amended Article 293 and Article 294 of the Dutch Penal Code. Article 293 addressed the practice of voluntary active euthanasia, while Article 294 amended the law on physician assisted suicide. Article 293(1) of the Dutch Penal Code now sets out that 'Any person who terminates another person's life at that person's express and earnest request shall be liable to a term of imprisonment not exceeding twelve years or a fifth category fine.'¹² On this basis, voluntary active euthanasia is not permitted in the Netherlands. An exception to this is provided by Article 293(2) of the Dutch Penal Code which stipulates that no legal penalty will apply in circumstances where the act is committed by a physician who satisfies the due care criteria set out in article 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act.¹³ In effect, if a doctor complies with Article 293(2) there would be 'nothing legally wrong'¹⁴ with their conduct. Similarly, physician assisted suicide is illegal under Article 294 of the Dutch Penal Code except in circumstances where the due care criteria have been complied with.¹⁵

The due care criteria reflect the case law on euthanasia in the Netherlands prior to the introduction of this Act.¹⁶ The due care criteria are satisfied in cases where the doctor:

- holds the conviction that the request by the patient was voluntary and well-considered,
- holds the conviction that the patient's suffering was lasting and unbearable,

8 Hoge Raad (Supreme Court of the Netherlands), 27 November 1984, NJ 1985, No. 106; J. De Haan, 'The new Dutch law on euthanasia' (2002) *Medical Law Review* 57, 59.

9 Hoge Raad (Supreme Court of the Netherlands), 21 June 1994, NJ 1994, 656.

10 Hoge Raad (Supreme Court of the Netherlands), 24 December 2002, NJ 2003, 167.

11 S. Gevers, 'Euthanasia: law and practice in The Netherlands' (1996) 52(2) *British Medical Bulletin* 326, 332.

12 Dutch Penal Code, Article 293(1).

13 Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, article 2.

14 De Haan (note 8) 58.

15 Dutch Penal Code, Article 294(2).

16 De Haan (note 8) 58–59 'The new Act on euthanasia is the result of a process of public debate and legal change in the Netherlands which has taken place during the last thirty or so years.'; *Carter v Canada (Attorney General)* 2012 BCSC 886, [457] 'The Dutch Act is in part the codification of a permissive regime that had developed through a series of judicial decisions and professional guidelines issued over the preceding three decades.'

- has informed the patient about the situation he was in and about his prospects, and the patient hold the conviction that there was no other reasonable solution for the situation he was in,
- has consulted at least one other, independent physician who has seen the patient and has given his written opinion on the requirements of due care,
- has terminated a life or assisted in a suicide with due care.¹⁷

These criteria must all be met in order to comply with the exemption provided by Article 293(2) of the Dutch Penal Code. The most challenging of these criteria may be the need to recognise suffering which is ‘lasting and unbearable’. The challenges presented by this criterion are demonstrated in case law prior to and subsequent to the introduction of the Act of 2001.

Defining ‘lasting and unbearable suffering’

Article 293(2) of the Dutch Penal Code requires Dutch physicians to be able to identify ‘suffering’ and to recognise when that suffering is ‘lasting’ and ‘unbearable’. The term ‘suffering’ is defined in a position paper on euthanasia published by the Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association) (KNMG) as ‘the experience of pain or distress’.¹⁸ This is a broad definition and underlines the subjective nature of deciding what level of pain or distress is ‘unbearable’ and ‘lasting’. Pain is an inherently personal experience and the input of the patient is therefore invaluable in informing this requirement. This is also seen in palliative sedation where the identification of a refractory symptom is closely tied to what is tolerable for the individual patient. In relation to ‘lasting’ suffering, the KNMG position paper suggests that this will be significantly influenced by the ‘physician’s professional opinion about the treatment and care options still available to the patient’.¹⁹ Additional concerns which can be factored in to a decision include the likely trajectory of the disease,²⁰ whether there is ‘loss of function’,²¹ and the nebulous concept of whether the patient could still ‘lead a meaningful life’.²² The KNMG position paper and the corresponding legislation clearly provides a broad range of discretion to the physician in identifying ‘lasting’ suffering. Furthermore, the lack of a clearly defined timeframe in the legislation or in the KNMG position paper suggests that the doctor is to look beyond a timescale and consider the cumulative impact of an illness on a person’s life.

17 Dutch Penal Code, Article 293(2).

18 KNMG, ‘The role of the physician in the voluntary termination of life’ (June 2001) 20; KNMG (note 18) 13 ‘The purpose of this memorandum is to present the KNMG’s current standpoint on the role, responsibilities, possibilities and limitations that physicians have with regard to the issue of the voluntary termination of life.’

19 Ibid. 20.

20 Ibid. ‘Is it likely that the patient’s condition will improve to a satisfactory degree? Or is it more likely that it will only deteriorate?’

21 Ibid.

22 Ibid.

The criterion that the suffering be 'unbearable' is equally difficult to accurately characterise. The KNMG position paper sets out that '[t]he question of whether suffering is unbearable is one that only the patient can answer.'²³ Although this quote emphasises the subjective nature of pain, it is the doctor who makes the final decision. The doctor must be satisfied as to the nature of the suffering as well as its duration. For a majority of patients the source of suffering is due to 'somatic problems and ailments, with 80–90% of notified cases concerning malignancies.'²⁴ This demonstrates that lasting and unbearable suffering may also have a non-somatic origin.²⁵ The manner in which non-somatic suffering such as existential distress is treated is particularly challenging. This point was highlighted in Chapter 1 in the context of palliative sedation but it has also posed challenges for the Dutch Penal Code. The issue of non-somatic suffering arose in the cases of *Chabot* and *Brongersma*.

In *Chabot*, a psychiatrist assisted in the death of a 50-year-old woman who was named as Mrs B.²⁶ Dr Chabot had several meetings with Mrs B which lasted 24 hours in all, and spoke with Mrs B's sister and brother-in-law.²⁷ On a number of occasions, Dr Chabot discussed the case with several consultants and provided them with a detailed account of the situation so as to illicit suggestions on issues which the psychiatric investigation of Mrs B may have neglected. Dr Chabot was of the opinion that Mrs B was 'experiencing intense, long-term psychic suffering that, for her, was unbearable and without prospect of improvement.'²⁸ In addition, Dr Chabot believed that the woman's request for assisted suicide was thought out and reflected an understanding of her situation and the implications of her decision.

Dr Chabot concluded that the only solution was to act to bring about the death of the patient. Dr Chabot was prosecuted and acquitted in the first instance and on appeal. The case came before the Supreme Court which 'refused to distinguish between psychological and physical suffering, as proposed by the prosecution.'²⁹ In effect, the Court interpreted the experience of pain and suffering in a broad manner. For example, the case demonstrated that the identification of suffering can be 'abstracted from its cause'.³⁰ The administration of sedation for existential

23 Ibid.

24 Ibid. 21; H. Marcovitch (ed), *Black's Medical Dictionary* (41st edn, A & C Black Publishers 2005) 656. Somatic can be understood as referring to the 'body rather than the mind'.

25 M.L. Lanza, 'Nurses as patient assault victims: an update, synthesis, and recommendations' (1992) 6(3) *Archives of Psychiatric Nursing* 163 cited by I. Needham and others, 'Non-somatic effects of patient aggression on nurses: a systematic review' (2005) 49(3) *Journal of Advanced Nursing* 283, 284. Non-somatic effects were identified as 'bio-physiological, emotional, cognitive, and social reactions'.

26 Hoge Raad (Supreme Court of the Netherlands), 21 June 1994, NJ 1994, 656.

27 J. Griffiths, 'Assisted suicide in the Netherlands: the Chabot case' (1995) 58(2) *Modern Law Review* 232, 234.

28 Ibid. 235.

29 U. De Vries, 'Can a legal right to euthanasia exist? A Dutch perspective on a universal medico-ethical dilemma' (2003) 9(1) *Medico-Legal Journal of Ireland* 24, 25.

30 Ibid. 26.

distress and restlessness alone is controversial as it would be treating psychological distress rather than physical pain experienced by the patient. Nevertheless, there are those who argue that if existential distress and emotional suffering are not being adequately controlled then palliative sedation should be available to the patient. Among the opposing arguments is that existential suffering may occur when a patient is not imminently dying. The provision of palliative sedation in such an instance would be outside the typical criteria for refractory symptoms and would therefore blur the distinction between specialist palliative care practices and euthanasia.

The limits of euthanasia in the Netherlands were again tested in *Brongersma*.³¹ In contrast to *Chabot*, the case of *Brongersma* was heard during and after the introduction of the 2001 Act.³² Mr Brongersma suffered from his physical deterioration and a feeling of senselessness in his existence. In April 1998 Mr Brongersma committed suicide with the assistance of his doctor, Philip Sutorius.

The key issue in *Brongersma* was the legality of assisted suicide for existential suffering. The District Court accepted the opinion that Mr Brongersma's suffering was unbearable and hopeless. This led to the acquittal of Dr Sutorius. However, the Court of Appeals reversed the decision of the District Court and Dr Sutorius was convicted for 'purposefully aiding another person to commit suicide and providing him with the means to do so, resulting in the suicide.'³³ On appeal, the Supreme Court followed this ruling but did not impose any penalty on the doctor for his involvement. The approach taken by the Supreme Court demonstrated that the suffering of a patient 'should have its principal basis in one or more medically classifiable somatic or psychological illnesses or conditions.'³⁴ This suggests that euthanasia is accepted in the Netherlands provided that the non-somatic condition is 'medically classifiable'.³⁵ The result of this is that many patients may come within the due-care criteria for euthanasia based on how their mental suffering is classified. This is reflected in a broader interpretation by doctors as to what constitutes 'lasting and unbearable suffering.'

The KNMG position paper suggests that a 'less restrictive'³⁶ approach began after the ruling in *Brongersma*. This position paper also suggests that issues such as 'loss of function, loneliness and loss of autonomy'³⁷ may form part of the discussion in considering a request for euthanasia. At any rate, it is evident from the cases of *Chabot* and *Brongersma* that the treatment of mental suffering is a complex and highly sensitive issue.

31 Hoge Raad (Supreme Court of the Netherlands), 24 December 2002, NJ 2003, 167. Mr Brongersma was a former lawyer and Senator in the Netherlands.

32 S.J. Youngner and G.K. Kimsma, *Physician-Assisted Death in Perspective: Assessing the Dutch Experience* (Cambridge University Press 2012) 59 'The first trial took place in October 2000, on the same day as initial parliamentary deliberation on the government's bill.'

33 KNMG (note 18) 10.

34 Ibid.

35 Ibid.

36 Ibid. 26.

37 Ibid. 40.

There are clear points of convergence between forms of euthanasia and palliative sedation. First, in cases of voluntary active euthanasia and palliative sedation the patient must be suffering unbearably. This manifests as a refractory symptom in the context of specialist palliative care. On this point, the manner in which non-somatic suffering such as existential distress is treated is of considerable importance in defining the legitimacy of the distinction between specialist palliative care and euthanasia. Inconsistency in the treatment of non-somatic suffering serves to add weight to claims that palliative sedation is a form of 'slow euthanasia'. Second, in both euthanasia and palliative sedation the patient's suffering should be untreatable in the circumstances. Under the 2001 Act, the doctor and the patient are to 'hold the conviction that there was no other reasonable solution for the situation ...'.³⁸ Similarly, the refractory symptom is one 'for which all possible treatment has failed or it is estimated that no methods are available for palliation within the time frame and the risk–benefit ratio'³⁹ that is tolerable to the patient. This may lead to palliative sedation being justified on the basis of being a treatment of last resort. The cumulative effect is to demonstrate that there are circumstances where the indications for each practice appear to overlap. This does not however mean that they are functionally equivalent. Nonetheless, when combined with suggestions that palliative sedation hastens the death of a patient it raises the potential for criminal liability. In addition to the justification of last resort, the doctrine of double effect is regularly called on as a justification for palliative sedation. A fundamental aspect of this justification is the concept of intention. It is therefore necessary to set out the legal test for 'intention' before examining its application in the ethical justification of double effect.

2.2 Murder: identifying the requisite intention

The offence of murder is effectively made up of three elements which are the *actus reus*, *mens rea*, and the lack of a valid defence.⁴⁰ The *actus reus* refers to 'what the defendant must be proved to have done (or sometimes failed to do), in what circumstances, and with what consequences.'⁴¹ The *actus reus* can be performed by an action or an omission. The circumstances in which an omission may satisfy the *actus reus* requirement will be set out in the third section of this chapter when discussing treatment withdrawal. The *mens rea* refers to the mental element of a crime.⁴² The mental element may either be a specific intention to kill a person or that bringing about a person's death is foreseen as a virtual certainty of an

38 Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001, Article 2(1).

39 M. Maltoni and others, 'Palliative sedation in end-of-life care' (2013) 25(4) *Current Opinion in Oncology* 360, 362.

40 D. Lanham, 'Larsonneur revisited' (1976) *Criminal Law Review* 276, 276.

41 J. Herring, *Criminal Law: Texts, Cases, and Materials* (2nd edn, Oxford University Press 2012) 85.

42 Ibid. 146 '*Mens rea* is the legal term used to describe the element of the criminal offence that relates to the defendant's mental state.'

individual's actions. It is the latter, indirect intention, which is of most relevance in cases of palliative sedation.

In England and Wales there is no definition of intention set out in legislation. Instead, the concept has been refined through case law. In *R v Woolin*, Lord Steyn stated that the jury are 'not entitled to find the necessary intention unless they feel sure that death or serious bodily harm was a virtual certainty ... as a result of the defendant's actions and that the defendant appreciated that such was the case.'⁴³ This gives the jury scope to find that a defendant did not intend the consequences which flowed from his actions despite foreseeing them as a virtual certainty. As Ashworth commented:

... if courts are only 'entitled' to find intention in these cases, then they might lawfully decide not to find intention despite foresight of virtual certainty. Once again, the highest court in the land has declined to affirm, clearly, that intention includes both purpose and foresight that a particular consequence will occur in the ordinary course of events.⁴⁴

In Ireland, the mental element for murder is set out by section 4 of the *Criminal Justice Act 1964*. This section provides that:

- (1) Where a person kills another unlawfully the killing shall not be murder unless the accused person intended to kill, or cause serious injury to, some person, whether the person actually killed or not.
- (2) The accused person shall be presumed to have intended the natural and probable consequences of his conduct; but this presumption may be rebutted.⁴⁵

Guidance on the meaning of 'intention' in the Criminal Justice Act 1964 can be found in *People v Murray*.⁴⁶ This was the first Irish case to examine the meaning of 'intention'.⁴⁷ Walsh J in the Supreme Court decision of *People v Murray* noted that 'To intend to murder, or to cause serious injury ... is to have in mind a fixed purpose to reach that desired objective.'⁴⁸ In effect, for there to be intention there must be foresight as well as willing the probable consequences of his conduct.⁴⁹ In his judgment, Walsh J also distinguished the elements of intention, foresight of consequences, and recklessness. For example, Walsh J noted that 'foresight of probable consequences must be distinguished from recklessness which imports a

43 *R v Woolin* [1998] 4 All E.R. 103, 113.

44 A. Ashworth, *Principles of Criminal Law* (3rd edn, Oxford University Press 1999) 180.

45 Criminal Justice Act 1964, s 4.

46 *The People (DPP) v Murray* [1977] IR 360.

47 Criminal Justice Act 1964, s 4.

48 *The People (DPP) v Murray* [1977] IR 360, 386.

49 *Ibid.*

disregard of possible consequences.⁵⁰ The effect of this is to demonstrate that the mens rea for murder is confined to a specific intention to kill or to bring about very serious injury. Foresight that a person's actions are likely to kill does not appear to be the same as intention. This point is central to the distinction between sedative drugs given for the purpose of addressing a patient's pain as opposed to the administration of sedative drugs with the direct intention of hastening a patient's death. Nevertheless, in certain circumstances the healthcare professional may foresee the potential for hastening the patient's death but act with the intention of easing the patient's pain. This highlights the crux of this issue as people may act with a variety of intentions and the identification of a specific intention is not a straightforward task.

The meaning of intention was subsequently discussed by the Court of Criminal Appeal in Ireland in *The People (DPP) v Douglas and Hayes*.⁵¹ Although the discussion of 'intention' in this case was obiter, it is helpful in understanding the concept of 'intention' in the Irish jurisdiction. The Court of Criminal Appeal noted that 'unless an accused has actually expressed an intent to kill, his intent can only be ascertained from a consideration of his actions and the surrounding circumstances.'⁵² In specialist palliative care this may involve consideration of the patient's medical history, notes made on the patient's chart, or conversations with other healthcare professionals regarding the treatment and care of a patient.⁵³ The Court of Criminal Appeal held that foresight and recklessness was not the equivalent of intention but they could potentially be 'evidence from which an inference of intention could be drawn.'⁵⁴

Section 4(2) of the Criminal Justice Act 1964 establishes a rebuttable presumption that the accused is 'to have intended the natural and probable consequences of his conduct.'⁵⁵ A similar provision is section 8(a) of the Criminal Justice Act 1967 in England and Wales which provides that 'a court or jury in determining whether a person has committed an offence, – (a) shall not be bound to infer that [a person] intended or foresaw a result of his actions by reason only of its being a natural and probable consequence of those actions.'⁵⁶ The section 4(2) presumption should be approached by the jury in two parts. The first part is to determine whether the natural and likely consequence was to bring about death or serious injury. If this is answered in the affirmative the next step is to consider whether the presumption is successfully rebutted by the accused. The doctrine of

50 Ibid. 387.

51 *The People (DPP) v Douglas and Hayes* [1985] IRLM 25.

52 Ibid. 27.

53 J. Boyle, 'Medical ethics and double effect: the case of terminal sedation' (2004) 25 *Theoretical Medicine* 51, 51–52 'Evidence of physician intent can be found in notations on the patient's chart and in the recorded dosages and titration of analgesics.'

54 Law Reform Commission, Report on Homicide: Murder and Involuntary Manslaughter (LRC 87–2008) 33; *The People (DPP) v Douglas and Hayes* [1985] IRLM 25.

55 Criminal Justice Act 1964, s 4(2).

56 Criminal Justice Act 1967, s 8.

double effect is a means by which the presumption may be rebutted as ‘the requisite *mens rea* for murder will not have been established.’⁵⁷ This has led to double effect being described as ‘an ethical cornerstone in the medical treatment of the terminally ill.’⁵⁸ It also underlines the necessity of examining not only the application of the doctrine of double effect but also the validity of the doctrine.

2.3 The legal and ethical justification of specialist palliative care practices

Specialist palliative care practices have been justified in a variety of ways. However, this section will primarily focus on the doctrine of double effect and the acts and omissions distinction. Reference will also be made to other justifications such as proportionality, last resort, and patient autonomy. The inherent limits of these justifications will be highlighted as will the contribution which they can make to framing the legal status of palliative sedation and the withholding and withdrawal of ANH. The influence of patient autonomy will be further explored in Chapter 3 as part of a larger discussion on human rights in palliative care.

2.3.1 The doctrine of double effect

It would be incorrect to speak of a single doctrine of double effect.⁵⁹ Rather, there are differing perspectives on the interpretation and application of the doctrine. A simple interpretation is that it is a doctrine which ‘distinguishes between the consequences which are intended and those which might be foreseen but are not intended.’⁶⁰ Double effect is therefore called upon as a justification in circumstances where the actions of a healthcare professional in administering palliative sedation appear to demonstrate some of the characteristics normally associated with euthanasia.⁶¹ In this regard, Foster et al. suggested that the focus

57 S. Ost, ‘Euthanasia and the defence of necessity: advocating a more appropriate legal response’ (2005) *Criminal Law Review* 355, 356.

58 T.E. Quill, ‘The ambiguity of clinical intentions’ (1993) 329(14) *The New England Journal of Medicine* 1039, 1039; Double effect has been described as ‘immense practical importance’ by D.P. Sulmasy and E.D. Pellegrino, ‘The rule of double effect: clearing-up the double talk’ (1999) 159(6) *Archives of Internal Medicine* 545, 545.

59 D.B. Marquis, ‘Four versions of double effect’ (1991) 16 *The Journal of Medicine and Philosophy* 515, 515 ‘There is no longer *one* doctrine of double effect.’ (emphasis in original).

60 J. Lombard, ‘Sedation of the terminally ill patient: the role of the doctrine of double effect’ (2015) 21(1) *Medico-Legal Journal of Ireland* 22, 24; L.A. Jansen and D.P. Sulmasy, ‘Sedation, alimentation, hydration, and equivocation: careful conversation about care at the end of life’ (2002) 136(11) *American College of Physicians-American Society of Internal Medicine* 845, 847 ‘The rule of double effect calls attention to the moral difference between bringing about harm as merely a foreseen effect of an action aimed at some good end and intentionally bringing about harm as a means to that end.’

61 G. Williams, ‘The principle of double effect and terminal sedation’ (2001) 9 *Medical Law Review* 41, 44 ‘It is a justification (rather than an excuse) because “justification is founded on the law’s preference for one course of action, rather than another”.’

placed on the doctrine by academics and practitioners 'is best explained by its tremendous practical utility'.⁶² However, the utility is dependent on the manner in which the doctrine is interpreted and applied. This section will outline the origins and development of double effect, along with the criteria for the doctrine, and will examine the way in which the doctrine has been interpreted by the courts.

2.3.1.1 *The development of double effect reasoning*

The origin of the doctrine of double effect has been credited to Thomas Aquinas in his discussion on self-defence.⁶³ Aquinas set out that:

Nothing hinders one act from having two effects, only one of which is intended, while the other is beside the intention. ... Accordingly, the act of self-defence may have two effects: one, the saving of one's life; the other, the slaying of the aggressor.⁶⁴

Such acts may be justified provided there is an element of proportionality, e.g. 'though proceeding from a good intention, an act may be rendered unlawful if it be out of proportion to the end.'⁶⁵ Aquinas did not set out to establish the basis of the doctrine of double effect but was instead concerned with intention as a way to understand God better.⁶⁶ This reflects the Catholic origins of the doctrine which had a considerable influence on its development. The doctrine of double effect has continued to be modified in various respects over the years and there is no single correct version of this doctrine.

The next contributor to the doctrine of double effect in the Catholic faith has been identified as Cardinal Cajetan.⁶⁷ His interpretation of double effect can be said to reflect more recent interpretations of the doctrine.⁶⁸ The work of the Salmanticenses has also been influential in the development of the doctrine of double effect.⁶⁹ In particular, their approach to the doctrine served to expand it to 'the whole field of moral theology'⁷⁰ instead of restricting it to self-defence. An

62 C. Foster and others 'The double effect effect' (2011) 20 *Cambridge Quarterly of Healthcare Ethics* 56.

63 T. Aquinas, *Summa Theologica* (Fathers of the English Dominican Province tr, Benziger Brothers 1947) (II-II, Qu. 64, Art.7); See also J.T. Mangan, 'An historical analysis of the principle of the double effect' (1945) *Theological Studies* 41.

64 Aquinas (note 63) 1471.

65 Ibid.

66 Foster (note 62) 57.

67 Mangan (note 63) 52.

68 Ibid. 'There is no doubt in the wording of Cajetan, that he interprets II-II, q. 64, a. 7 in terms of the principle of the double effect as we understand it today.'

69 Salmanticenses, *Cursus Theologicus* (Brussels 1879); Mangan (note 63) 57; Foster (note 62) 57.

70 Mangan (note 63) 56.

updated approach to double effect was set out in 1874 by Gury,⁷¹ and a formulation of double effect was set out by the Catholic scholar, Joseph Mangan, in 1949.⁷² Mangan suggests that the uncertainty around the doctrine of double effect is reflective of a broader inconclusiveness about the content of the morally good action.⁷³ This reflects the fact that it is not possible to achieve universal agreement on what constitutes an exceptionless morally proper action as people will view the issue through disparate frameworks. For example, Raus et al. identify three distinct groupings, namely ‘thinkers who adhere to the classical interpretation of DDE and situate themselves within the natural law tradition’,⁷⁴ thinkers outside the natural law tradition,⁷⁵ and proportionalists.⁷⁶ Huxtable and Horn suggest there are two categories in the interpretation of double effect, namely consequentialist and deontological perspectives. For instance, ‘[p]roponents appear to take a deontological line, in which duties, rights and intentions dominate, rather than consequences as such, while many opponents tend to adopt a consequentialist perspective, in which right and wrong are judged in terms of outcomes.’⁷⁷ The framework adopted has a significant impact on the applicability of double effect reasoning to cases of palliative sedation.

2.3.1.2 The criteria for double effect

The criteria for double effect can be set out as follows:

- 1 The act must be morally good, or, at a minimum, it should be neutral.
- 2 The bad effect should not be the means through which the good effect is achieved.
- 3 The bad effect is foreseen and tolerated whereas it is the good effect which is directly intended.
- 4 The reasons for carrying out the good act must exceed the unintended bad effect.⁷⁸

These points must be satisfied if the doctrine of double effect is to provide a justification. However, palliative sedation raises particular problems for the

71 J.P. Gury, *Compendium Theologiae Moralis* (5th edn, Ratisbon 1874) quoted in Mangan (n134) 57.

72 Mangan (note 63) 43.

73 Ibid. 41.

74 K. Raus and others, ‘Can the Doctrine of Double Effect Justify Continuous Deep Sedation at the End of Life?’ in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 179.

75 Ibid.

76 Ibid.

77 R. Huxtable and R. Horn, ‘Continuous Deep Sedation at the End of Life: Balancing Benefits and Harms in England, Germany and France’ in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 172.

78 Lombard (note 60) 24; See also T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 154.

concept of double effect and it has been described as being 'unjustified',⁷⁹ 'hypocritical',⁸⁰ and 'sophistic'.⁸¹ It was noted by Beauchamp and Childress that palliative sedation 'challenges the boundaries and use of the [rule of double effect].'⁸² Palliative sedation may well push at the boundaries of palliative care due to uncertainty surrounding the precise timing of death, and the difficulty of assessing the relationship of physiological and pharmacological factors to the demise of the patient.⁸³ Beauchamp and Childress summarised this issue in stating that:

Much depends on the description of terminal sedation in a particular set of circumstances, including the patient's overall condition, the proximity of death, and the availability of alternative means to relieve pain and suffering, as well as the intention of the physician and other parties.⁸⁴

The intention of the healthcare professional in administering palliative sedation may be a stumbling block in the effective application of the doctrine. This will be considered when discussing the third criterion for double effect. Nonetheless, the other criteria for the doctrine also raise distinct challenges of interpretation and application, all of which underline the complexity of applying the doctrine of double effect to palliative sedation in practice.

(A) THE ACT MUST BE MORALLY GOOD, OR, AT A MINIMUM, IT SHOULD BE NEUTRAL

The first criterion for double effect is that the act must be morally good, or, at a minimum, it should be neutral. The question which then arises is how the administration of the sedative drug is to be categorised. Determining the moral quality of an act will generally be determined in accordance with the framework through which the act is examined. As the act is one of pain relief for the terminally ill patient the act can be perceived as morally good. This line of reasoning has been followed by Williams⁸⁵ and Foster⁸⁶ who suggest that relieving the pain

79 E. Young, 'Ethical issues at the end of life' (1998) 9 *Stanford Law and Policy Review* 267 cited by Williams (note 61) 52; T.E. Quill and others, 'The rule of double effect: a critique of its role in end-of-life decision-making' (1997) 337 *New England Journal of Medicine* 1768, 1771 'the rule's absolute prohibitions, unrealistic characterization of physicians' intentions, and failure to account for patients' wishes make it problematic in many circumstances.'

80 A.M. Begley, 'Acts, omissions, intentions and motives: a philosophical examination of the moral distinction between killing and letting die' (1998) 28(4) *Journal of Advanced Nursing* 865, 873.

81 T. Helme and N. Padfield, 'Setting euthanasia on the level' (1993) 15 *Liverpool Law Review* 75, 83.

82 Beauchamp (note 78) 168 RDE stands for rule of double effect.

83 M. Ashby, 'Death Causation in Palliative Medicine' in Ian Freckelton and Danuta Mendelson, *Causation in Law and Medicine* (Ashgate Dartmouth 2002) 228, 236.

84 Beauchamp (note 78) 168.

85 Williams (note 61) 50.

86 Foster (note 62) 59 'For example, when applying the doctrine to giving pain relief (with the possibility of shortening life), the act of pain relief itself is clearly good.'

experienced by a person is morally good. The remaining criteria are not as easily satisfied and draw out the underlying legal, ethical, and clinical challenges posed by this practice.

(B) THE BAD EFFECT SHOULD NOT BE THE MEANS THROUGH WHICH THE GOOD EFFECT IS ACHIEVED

The second criterion requires that the negative effect should not be the means through which the good effect is achieved. The negative effect could take several forms and may include the death of the patient, hastening the death of the patient, or the reduction in consciousness. Although the death of a patient would eliminate pain, it is not how sedative drugs function. As Dr Tony O'Brien noted in *Fleming v Ireland*, it would be 'entirely radical for a physician to attempt to kill the pain by killing the patient.'⁸⁷ Bringing about the death of the patient is not necessary for the achievement of the beneficial outcome in specialist palliative care. The definition of palliative care set out in Chapter 1 made it clear that this form of care focuses on the 'quality of life'⁸⁸ and the treatment of pain rather than seeking to bring about or hasten the death of a patient. Those who argue that palliative sedation is a form of 'slow euthanasia' may be of the opinion that sedation relieves pain by hastening death.⁸⁹ However, the shortening of life due to opioids has been described as a 'persistent fantasy',⁹⁰ and it was highlighted in Chapter 1 that an appropriate level of sedative drug is unlikely to hasten the death of the patient.⁹¹ This gives rise to a degree of tension in the application of double effect. If we were to maintain the position that no harm ever occurs in palliative sedation then the doctrine of double effect could not be utilised as there would be no 'bad effect'. However, if we accept that there are some occasions where a negative effect could potentially occur then double effect would be relevant. This places palliative medicine in a difficult position as reference to the doctrine reinforces suggestions that sedation results in harm to the patient. It suggests that there is something fundamental which must be excused or justified.

The suggested similarity between palliative sedation and euthanasia was the prevailing criticism of the practice in the early literature whereas the reduction of

87 *Fleming v Ireland & Ors* [2013] IEHC 2 [34].

88 Ibid [35]; C. Sepúlveda and others, 'Palliative care: the World Health Organization's global perspective' (2002) 24(2) *Journal of Pain and Symptom Management* 91, 94.

89 Williams (note 61) 50 'Although some people may perceive terminal sedation as the deliberate induction of coma to relieve suffering by hastening death. If this were the case, then condition two would obviously not be satisfied.'; Foster (note 62) 59 'Again note that the doctrine is only relevant if the first requirement is met: that the earlier death is seen in itself as a bad consequence.'

90 R. Twycross, 'Where There is Hope, There is Life: A View from the Hospice' in J. Keown (ed), *Euthanasia Examined* (Cambridge University Press 1995) 161.

91 *Fleming v Ireland & Ors* [2013] IEHC 2, [47] See comments of Professor Robert George, 'Finally, he concurred with Dr. O'Brien on the correct use of opioids and said that the notion that "by giving opioids at the very end of life we are bringing about death simply isn't true in our experience and the evidence doesn't support it at all."'

consciousness was seldom considered. This may have been due to the nexus between sedation and consciousness whereas the hastening of death was the more conspicuous harm. Despite this, the reduction in consciousness could constitute a direct or indirect harm.⁹² The effect of reducing the patient's consciousness until death effectively ends any possibility of making a contemporaneous decision in relation to their healthcare and concludes any further interaction with close friends and family. Battin set out that 'once the process has begun, the patient no longer has a way of controlling the course of events on the way to death: what had been a gain in patient autonomy is erased.'⁹³ The removal of consciousness has also been described as a form of social death.⁹⁴ This argument stems from a biographical or personhood-based account of death. The reduction of consciousness is fundamental to the practice of continuous sedation as demonstrated by the definitions of sedation in Chapter 1. It would therefore be difficult to describe the reduction in consciousness as an unintended side-effect. For instance, midazolam is one of the most commonly used sedative drugs and this has the function of reducing consciousness. The function and use of such sedative drugs links with the third criterion which is dependent on the intention of the healthcare professional.

(C) THE BAD EFFECT IS FORESEEN AND TOLERATED WHEREAS IT IS THE GOOD EFFECT WHICH IS DIRECTLY INTENDED

The third criterion requires that it is the good effect which is directly intended although the bad effect is foreseen and tolerated.⁹⁵ The potential negative effects were highlighted in the preceding paragraphs. The concept of intention is central to this criterion and, in turn, is central to the application of the doctrine. The intention of the healthcare professional should be directed towards the relief of suffering but the healthcare professional may recognise that the bad effect cannot

92 Raus (note 74) 190; W. Quinn, 'Actions, Intentions, and Consequences: The Doctrine of Double Effect' in W. Quinn, *Morality and Action* (Cambridge University Press 1993); F. Kamm, 'Physician-assisted suicide: the doctrine of double effect, and the ground of value' (1999) 109(3) *Ethics* 602.

93 M.P. Battin, 'Terminal Sedation: Recasting a Metaphor as the *Ars Moriendi* Changes' in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 249.

94 M.P. Davis and P.A. Ford, 'Palliative Sedation Definition, Practice, Outcomes, and Ethics' (2005) 8(4) *Journal of Palliative Medicine* 699; J.J.M. van Delden 'The ethical evaluation of continuous sedation at the end of life' in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 223; R. Janssens and others, 'Palliative sedation: not just normal medical practice. Ethics reflections on the Royal Dutch Medical Association's guideline on palliative sedation' (2012) 38(11) *Journal of Medical Ethics* 664.

95 Beauchamp (note 78) 167 'It is more suitable in these contexts to discard the language of "wanting" and to say that foreseen, undesired effects are "tolerated." ... In this conception a physician can desire not to do what he intends to do, in the same way that one can be willing to do something but, at the same time, reluctant to do it or even detest doing it.'

be avoided in the circumstances.⁹⁶ Beauchamp and Childress note that a supporter of double effect 'must elect a ... narrow conception of what is intended to avoid the conclusion that an agent intentionally brings about all the consequences of an action that the agent foresees.'⁹⁷ This narrow conception of intention is problematic as it suggests that other intentions which are present are deliberately disregarded or excluded. It is possible that the healthcare professional acts with multiple intentions including intending to provide pain relief or an intention to hasten death. There is also the issue of how the healthcare professional frames or wishes to have their intention perceived at the time of administering sedative drugs. For instance, Ost suggested that reliance is placed on the physician to state his/her intention truthfully⁹⁸ and this 'cannot be easily resolved.'⁹⁹

The potential spectrum of intentions is highlighted in research by Chambaere et al. which examined sedation in Belgium.¹⁰⁰ Various respondents to the survey indicated that sedation had previously been administered with no intention to hasten death, a recognition that death could possibly be hastened, a co-intention or explicit intention to hasten death. Rietjens et al. also demonstrated instances where the hastening of death was partly the intention or the explicit intention of the physician.¹⁰¹ In this research, it was shown that in 47% of cases the hastening of death was partly the intention of the physician while it was the explicit intention in 17% of cases. These figures seem particularly high, especially when contrasted with research by Swart et al. which examined the experience of physicians and nurses in administering continuous palliative sedation in the Netherlands. In 85% of cases there was no intention to hasten death, in 14% of cases there was a partial intention, and in 1% of cases there was an explicit intention.¹⁰² Although these studies illustrate a divergence in the prevalence of certain intentions they also underline the need to accurately determine what intention was present when administering the sedative drug. This gives rise to arguments that intention in such

96 A. Thorns, 'The Use of Sedation at the End of Life' in R. Worthington (ed.) *Ethics and Palliative Care: A Case Based Manual* (CRC Press 2002) 80 'Sedation provides a means of alleviating distress but with risks that may be justified. The intention behind sedation is good – to relieve distress and not to bring about the patient's death'.

97 Beauchamp (note 78) 166.

98 Ost (note 57) 356.

99 Ibid. 358–359; L.A. Jansen, 'Disambiguating clinical intentions: the ethics of palliative sedation' (2010) 35 *Journal of Medicine and Philosophy* 19, 19 'It is often claimed that the intentions of physicians are multiple, ambiguous, and uncertain – at least with respect to end-of-life care.'; C. Douglas and others, 'Managing intentions: the end-of-life administration of analgesics and sedatives, and the possibility of slow euthanasia' (2008) 22(7) *Bioethics* 388; Quill (note 58).

100 K. Chambaere and others, 'Continuous deep sedation until death in Belgium: a nationwide survey' (2010) 170(5) *Archives of Internal Medicine* 490.

101 J.A. Rietjens and others, 'Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands' (2004) 141(3) *Annals of Internal Medicine* 178.

102 S.J. Swart and others, 'Physicians' and nurses' experiences with continuous palliative sedation in the Netherlands' (2010) 170(14) *Archives of Internal Medicine* 1271, 1272.

cases is often ambiguous and cannot therefore be accurately determined thereby undermining any accurate application of the doctrine of double effect.¹⁰³ Regardless, intention in cases of palliative sedation is not assessed in an abstract manner.

The ability to consult patient charts, speak with other members of the care team, and consider the surrounding circumstances in such cases means that intention is not solely based on the doctor's stated intention. It has been suggested that the intention of the doctor can be gauged by asking whether 'less risky measures' could have been taken depending on the circumstances.¹⁰⁴ This does not mean that intention can always be clearly identified but does demonstrate that it is not an insurmountable challenge to the application of the doctrine.¹⁰⁵ It should also be remembered that specialist palliative care is generally provided by a multidisciplinary team which includes physiotherapists, social workers, and specialist palliative care nurses. The decision to administer sedative drugs will often involve consultation with members of the care team. Yet, much of the literature treats the decision to administer sedation as one which is made by a solitary healthcare professional and is devoid of any other professional input or oversight. The presence and involvement of the multidisciplinary team makes it more difficult for a single healthcare professional to act with the intention of hastening the death of the patient. Furthermore, the administration of sedation is a process rather than a once off decision. It requires careful monitoring from healthcare professionals to ensure the refractory symptom is being effectively controlled. The nature of the process therefore allows for intentions to evolve and for multiple intentions to exist and emerge over time. However, these intentions must be mapped back to the actions taken, to the function of the sedative drug, and the manner in which the initial decision to administer sedation was made. It is only through examining the broader mosaic of care that a more accurate description of intention emerges. Notably, the House of Lords Select Committee on Medical Ethics also addressed the subject of determining intention in the context of double effect. In the House of Lords Report it was stated that '[s]ome may suggest that intention is not

103 Jansen (note 99) 22 'Critics of the principle of double effect, at least as it is applied in the context of end-of-life palliative care, contend that the intentions of clinicians frequently are uncertain and ambiguous in this way. For this reason, they claim that the principle of double effect cannot function effectively as a guide for making ethical assessments of aggressive, extraordinary pain management techniques.'; S. Rys and others, 'The moral difference or equivalence between continuous sedation until death and physician-assisted death: word games or war games?' (2012) 9 *Bioethical Inquiry* 171, 179 'We submit that there are several flaws in the concept of intention, not only practical aspects (such as the external validation of physicians' intentions) but also theoretical and definitional aspects. One of the main problems with intention is its ambiguity.'

104 Torbjörn Tännsjö, 'Terminal Sedation: A Substitute for Euthanasia' in Torbjörn Tännsjö (ed.), *Terminal Sedation: Euthanasia in Disguise* (Springer 2010) 24.

105 Beauchamp (note 78) 168 'Such facts about the physician's motivation and character can make a decisive difference to a moral assessment of the action and the agent. But this moral conclusion can also be reached independently of the RDE.'

readily ascertainable. But juries are asked every day to assess intention in all sorts of cases, and could do so in respect of double effect.¹⁰⁶ These comments were made in response to suggestions that double effect was a cloak for euthanasia and it demonstrates that intention, albeit complex, is possible to identify.¹⁰⁷

The third criterion is more difficult to satisfy in circumstances where it is the reduction in consciousness which is the perceived harm. Raus et al. examine two formulations of the application of double effect which they term the Standard Vatican Case and the Non-Standard Vatican Case.¹⁰⁸ These formulations both exhibit considerable problems in applying the doctrine of double effect to cases of palliative sedation due to the reduction in consciousness. In relation to the Standard Vatican Case Raus et al. highlight the potential 'performative paradox',¹⁰⁹ which can arise where a person intends to administer CDS but does not intend to permanently remove consciousness. Similarly, in the Non-Standard Vatican Case when sedative drugs are administered for the purpose of reducing consciousness then it is 'unjustified and impermissible according to the Non-Standard Vatican application of DDE'.¹¹⁰ Attempts to sidestep this issue through redescription were also set out but again it was shown that there were weaknesses in this argument which undermined the application of the doctrine of double effect.

(D) THE REASONS FOR CARRYING OUT THE GOOD ACT MUST EXCEED THE UNINTENDED BAD EFFECT

The fourth criterion for double effect is based on proportionality. Sykes described proportionality as 'the key to ethical use of sedatives'¹¹¹ and proportionality has been emphasised in the existing guidelines on palliative sedation.¹¹² In this criterion the reasons for carrying out the good act must exceed the unintended bad effect. Again, the assessment of proportionality will be influenced by the framework used to determine what constitutes a good or bad effect.¹¹³ The

106 House of Lords, Report of the House of Lords Select Committee on Medical Ethics (Paper 21-1 of 1993–1994) [243] '... They would no doubt consider the actions of the doctor, how they compared with usual medical practice directed towards the relief of pain and distress, and all the circumstances of the case.'

107 Ibid. 'We reject that charge while acknowledging that the doctor's intention, and evaluation of the pain and distress suffered by the patient, are of crucial significance in judging double effect.'

108 Raus (note 74).

109 Ibid. 192.

110 Ibid. 195.

111 N.P. Sykes, 'Clinical Aspects of Palliative Sedation' in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 99; See also M.M. Dean and others, 'Framework for continuous palliative sedation therapy in Canada' (2012) 15 (8) *Journal of Palliative Medicine* 870; T.E. Quill and others, 'Last-resort options for palliative sedation' (2009) 151(6) *Annals of Internal Medicine* 421.

112 Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2009); Dean (note 111).

113 Foster (note 62) 60 'Thinkers differ as to the relative weight of values and the means by which to evaluate them. Whereas some, including Catholic theologians, will work within an ordering framework of prior convictions (for instance, that the sanctity of

administration of palliative sedation is unlikely to be the first sedative administered to the patient. The control of pain will have progressed through several stages, will have gradually increased over time, and may have been informed through use of sedation scales.¹¹⁴ On this basis, the careful titration of the sedative drug until there is adequate relief from the refractory symptoms could be considered proportionate.¹¹⁵ This frames the practice of palliative sedation as the relief of distress rather than the reduction of consciousness.¹¹⁶ This does not however negate the need to address the reduction of consciousness. Ten Have and Welie argue that the ‘the benefit of relief from such symptoms can outweigh the harm of unconsciousness.’¹¹⁷ Nevertheless, Raus et al. discussed the proportionalist approach and set out that ‘[t]his interpretation of DDE, ... is controversial and can be said to have more in common with moral theories that allow a lesser evil to be committed to stop or prevent a greater evil, than it has with classical DDE.’¹¹⁸ The doctrine of double effect is a precarious ethical justification for palliative sedation due to the range of interpretations. This raises the question of how courts have threaded the line between the justification and the concept of intention in criminal law.

2.3.1.3 *Double effect in the courts*

The doctrine has been referenced and alluded to in cases from the United States, Canada, and England and Wales. The application of the doctrine of double effect in the US was seen in *Vacco v Quill*. In this case, Justice Rehnquist stated ‘[j]ust as a state may prohibit assisting suicide while permitting patients to refuse unwanted lifesaving treatment, it may permit palliative care related to that refusal, which may have the foreseen but unintended “double effect” of hastening the patient’s death.’¹¹⁹ The Canadian case of *Rodriguez v British Columbia* underlined the primacy of intention in assessing the actions of the healthcare professional. For instance, Judge Sopinka ruled that:

... the distinction drawn here is one based upon intention – in the case of palliative care the intention is to ease pain, which has the effect of hastening death, while in the case of assisted suicide, the intention is undeniably to cause

life is the highest good around which all other goods can be organized), others have different criteria for assessing values.’

114 S.H. Bush and others, ‘The Richmond Agitation-Sedation Scale modified for palliative care inpatients (RASS-PAL): a pilot study exploring validity and feasibility in clinical practice’ (2014) 13 *BMC Palliative Care* 17; J.J. Arevalo and others, ‘Palliative sedation: reliability and validity of sedation scales’ (2012) 44(5) *Journal of Pain and Symptom Management* 704.

115 Williams (note 61) 50.

116 Sykes (note 111) 95 ‘A low initial dose is titrated higher against the response until distress is relieved, i.e. the dose used is proportional to severity of distress. Hence relief of distress is the endpoint, not a particular level of consciousness.’

117 H. ten Have and J.V.M. Welie, ‘Palliative sedation versus euthanasia: an ethical assessment’ (2014) 47(1) *Journal of Pain and Symptom Management* 123, 130.

118 Raus (note 74) 197.

119 *Vacco v Quill* (1997) 521 U.S. 793, 808.

death ... In my view, distinctions based upon intent are important, and in fact form the basis of our criminal law. While factually the distinction may, at times, be difficult to draw, legally it is clear.¹²⁰

These references to double effect reasoning are both relatively superficial and focus on the foreseen but unintended aspect of the doctrine. Neither represent a sustained engagement with the justification.

It has been suggested that the role of double effect in English case law was first acknowledged by Devlin J in *R v Adams*.¹²¹ In *R v Adams*, the doctor was on trial for the murder of an elderly patient. It was alleged by the prosecution that the doctor had killed the patient for the purposes of inheriting property which she had left him in her will, and that he had done so by injecting the woman with excessive doses of morphine. In discussing this case Devlin J commented that:

If the first purpose of medicine, the restoration of health, can no longer be achieved, there is still much for a doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life.¹²²

Devlin J also set out that if the defendant did some act which was capable of being murderous, if the requisite intent was present at the time, then the prosecution also needed to prove the intention to murder was present. This direction to the jury provided scope for the jury to acquit Dr Adams if they were of the opinion that the intention of the doctor was to relieve the pain experienced by the patient or that the drugs had the effect of hastening the patient's death due to the poor medical condition of the patient. As this was a direction to the jury it cannot be said that Dr Adams was making law.¹²³ Moreover, the criteria for double effect are not fully enunciated in the comments of Devlin J.¹²⁴ Foster et al. have argued that *R v Adams* did not actually introduce the doctrine of double effect in English law. In support of this argument, Foster et al. highlight that the term 'double effect' is not used by Devlin J.¹²⁵ The argument is not solely based on terminology and Foster et al. stated that 'to see Adams as introducing the doctrine of double effect into English law is reading far too much into a rather amorphous direction to a jury.'¹²⁶ Regardless of whether or not this particular case introduced the doctrine

120 *Rodriguez v British Columbia* [1993] 3 SCR 519, 1993 CanLII 519 (SCC) para 57.

121 *R v Adams* [1957] Crim LR 773; G. Williams, *Intention and Causation in Medical Non-killing: The Impact of Criminal Law Concepts on Euthanasia and Assisted Suicide* (Routledge-Cavendish 2007) 35; See also *Compassion in Dying v Washington* 79 F. 3d 790; 1996 US App Lexis 3944.

122 P. Devlin, *Easing the Passing* (The Bodley Head 1985) 171.

123 Foster (note 62) 60–61.

124 Ibid. 62 'Devlin J does not hint at, let alone discuss, either the second or the fourth element in Keown's formulation.'

125 Ibid.

126 Foster (note 62) 62.

of double effect into English law, there have been subsequent cases in which the doctrine was utilised as a defence.

The doctrine of double effect was employed unsuccessfully by the defence counsel in *R v Cox*.¹²⁷ Dr Cox was charged with the murder of one of his patients as he injected the patient with a slow-acting tranquiliser and potassium chloride.¹²⁸ The prosecution argued that the injection of potassium chloride did not have a therapeutic quality but was instead intended to hasten the death of the patient. This case centred around the issue of intention which was a contrast to *R v Adams* in which causation was to the fore. Although this case focused on issues of intention, it did not adopt a clear step-by-step approach to the doctrine of double effect. In any case, the injection of potassium chloride made the successful application of the doctrine particularly challenging for the defence counsel given its lethal nature and lack of pain-relieving qualities.

The doctrine of double effect was also raised in the case of *Moor*.¹²⁹ Dr Moor was charged with the murder of one of his patients. Dr Moor claimed that the death was due to the administration of diamorphine which had been given for pain relief. The patient in this case was not terminally ill and the post mortem revealed that 'up to six times the claimed amount of the drug was found in his body'.¹³⁰ However, this level did not seem to be consistent with the level of morphine found in other parts of the patient's body. Hooper J put a number of questions to the jury to assist in making their decision. Among the questions were whether 'Dr. Moor has caused his patient's death',¹³¹ whether Dr Moor had intended to do something other than relieve the suffering of the patient, and 'was the jury satisfied that the injection he gave to his patient was intended to kill?'.¹³² Ultimately, Dr Moor was found not guilty but this case demonstrates a disconnect between the approach to intention in case law and the criteria set out for the doctrine of double effect.

2.3.1.4 *The significance of double effect*

The criteria for double effect can be justified in cases where palliative sedation has been administered to a terminally ill patient who is near the end of life and is experiencing an uncontrolled refractory symptom. It can be argued that the act of pain relief is morally good, the sedative drug does not relieve pain by hastening death, and the intention of the healthcare professionals caring for the patient can be accurately determined. Nevertheless, if we perceive the reduction in consciousness as a harm then it becomes much more difficult to effectively apply the doctrine. This points to a larger problem which undermines the doctrine of

127 *R v Cox* (1992) 12 BMLR 38.

128 See also N. Robb, 'Death in a Halifax hospital: a murder case highlights a profession's divisions' (1997) 157 *Canadian Medical Association Journal* 757.

129 *Moor*, *The Times*, 12 May 1999.

130 Williams (note 121) 38.

131 *Ibid.*

132 *Ibid.*

double effect. It is the subject of multiple interpretations which creates inconsistency in practice. The framework being applied in each particular case will influence its utility as an ethical justification. There are several other drawbacks to the use of double effect. Criticism of the subjective nature of intention was highlighted in the earlier section, there are limits on who could avail of such a justification, and double effect is silent on consent.¹³³ Consequently, the discussion of double effect as an ethical justification and its application in case law suggests that double effect is impractical, inconsistent, and inappropriate to guide decisions about palliative sedation.

The cases cited in the above section have elements of double effect reasoning and are often cited in discussion of double effect but none examine the application of the doctrine in a head-on or sustained manner. The lack of judicial engagement with the doctrine was highlighted by Foster et al. It was noted that judges' references to double effect have often been:

in a slapdash, shorthand way, either failing to identify clearly or at all the constituents of the doctrine they say they are applying, or referring to versions of the doctrine that do not reflect the more common formulations.¹³⁴

Lord Mustill in *Bland* wrote that the doctrine of double effect has not 'been the subject of a specific decision but seems to have been generally assumed to be the law by criminal practitioners'.¹³⁵ Given the status of double effect it appears that many in the medical profession also hold a similar belief. This is problematic given the multiple interpretations of the doctrine. Much greater legal and ethical clarity is needed in distinguishing specialist palliative care from euthanasia so healthcare professionals have a clear understanding of what care can be provided to the terminally ill patient.

It has been suggested by Sulmasy and Pellegrino that it is important that the principle be retained on the basis that its absence might result in some physicians who are opposed to euthanasia opting to avoid administering sedatives or opioids due to a 'fear of hastening death and committing euthanasia'.¹³⁶ This suggests that double effect is readily applied in courts whereas the reality was shown to be much different. Moreover, it was set out that the reduction of consciousness is likely to be the most prevalent harm in palliative sedation and this is unlikely to dissuade practitioners from administering sedation in circumstances where the patient experiences a refractory symptom. In any case, the intention of the healthcare professional can still be assessed outside of the doctrine and, as noted

133 D.M. Dudzinski, 'The principle of double effect in palliative care: euthanasia by another name?' in G.A. van Norman and others, *Clinical Ethics in Anesthesiology* (Cambridge University Press 2011) 88 'DE is silent on consent. Instead, DE revolves around intention.'

134 Foster (note 62) 66.

135 *Airedale N.H.S. v Bland* [1993] AC 789, 892 cited in *R(Nicklinson) v Ministry of Justice* [2013] HRLR 36 [26].

136 Sulmasy (note 58).

above, is something which the courts are regularly tasked with. Nambisan set out a list of steps which healthcare professions should follow to clarify the nature of their intention in administering sedative drugs. Several of these points have been mentioned already while others will be drawn out in subsequent sections and chapters. The steps are as follows:

Act within accepted practice guidelines, with a proportional approach.

Document clearly and fully.

Make sedation decisions as part of a multidisciplinary team.

Where possible, involve patient and carers in sedation decisions.

Show a clear indication for use of sedation, with consideration of alternatives.

Demonstrate consideration of using ANH.

Note evidence that patient is already near to dying.¹³⁷

In sum, the reliance on double effect as a justification for palliative sedation reinforces the suggestion that there is a link between euthanasia and specialist palliative care. It suggests there is a practice which needs to be justified or excused and it does not represent a good compromise position for those on either side of the debate. The status afforded to double effect in the context of palliative medicine does not reflect the reality of sedative practices. Regardless of the broader issues and criticisms surrounding the doctrine, it is wholly inappropriate for palliative sedation to be guided by an ethical justification. The doctrine of double effect therefore provides a justification but no real guidance on appropriate medical treatment and care. Consequently, it is necessary to reflect on how the legal framework for these practices is structured and how it can provide consistency and clarity for both the healthcare professional and the patient.

2.3.2 Palliative sedation without artificial nutrition and hydration

The withdrawal of ANH often accompanies palliative sedation but it is necessary to distinguish the two as they are ‘separate decisions supported by different legal and ethical principles.’¹³⁸ Although the decisions are distinct, if sedation is to be administered then a decision will need to be made about the provision of ANH. A sedated patient cannot take hydration or nutrition orally. The decision to commence the administration of palliative sedation does not mean that artificial nutrition and hydration must be withheld or withdrawn. This point was noted by Dr O’Brien in *Fleming v Ireland* when he commented that palliative sedation does

137 V. Nambisan, ‘Providing evidence of intention when giving palliative sedation’ (2012) 19(1) *European Journal of Palliative Care* 93 cited in Sykes (note 111) 99.

138 S. Gevers, ‘Terminal sedation: a new legal approach’ (2003) 10 *European Journal of Health Law* 359, 364; Maltoni (note 39) 365 ‘The decision-making processes to start palliative sedation and to stop nutrition and hydration are actually two different processes.’; ten Have (note 117) 131 ‘... the decision to forgo AN&H is independent of the decision to initiate palliative sedation.’

not necessarily involve the withdrawal of ANH.¹³⁹ Nonetheless, the proximity of these decisions can lead to suggestions that a single decision is taken and the distinction between the practices is ignored. On this point, the focus can be placed on why the patient is not able to take nutrition and hydration naturally. It has been argued that if the patient has been sedated to the point requiring the administration of ANH then it is 'the physician-created state of diminished consciousness that renders the patient unable to eat, not the patient's underlying disease.'¹⁴⁰ In such a case, if ANH is removed from a sedated patient it may be a leap in logic to attribute the death to the original illness rather than the removal of treatment. This leads some people to argue that palliative sedation without ANH should be considered as a single practice. However, as noted above ANH does not necessarily have to be withdrawn or withheld when sedation is initiated. This section therefore emphasises the distinct nature of the decision by reflecting on the legal justification underpinning the decision to withdraw or withhold treatment in the context of palliative care. The decision to withdraw or withhold ANH can be made in several ways. It can be based on the patient's refusal of treatment or, an assessment of a patient's best interests in circumstances where they lack capacity. This underlines the distinction in how palliative sedation and the withdrawal of ANH are justified.¹⁴¹

The experience of treatment withdrawal varies between countries. Research by Miccinesi et al. demonstrated that among patients receiving continuous deep sedation, 35% of patients in Italy and as many as 64% of patients in Denmark and the Netherlands did not receive ANH.¹⁴² As a percentage of the total patient population these figures do not appear as high but are still significant. For instance, continuous deep sedation without ANH occurred in 3.2% of Belgian cases, 1.6% in Denmark, 3% in Italy, 3.7% in the Netherlands, 1.8% in Sweden, and 2.9% in Switzerland.¹⁴³ This research underlines the proximity of decisions on sedation and ANH. Claessens et al. examined sedation in Flemish palliative care units. This research also highlighted the low level of ANH provision, e.g. '[a]t the start of sedation, three patients (15%) still received artificial fluids and continued to do so until the day of death. None of the patients received artificial

139 *Fleming v Ireland & Ors* [2013] IEHC 2, [37].

140 D. Orentlicher, 'The Supreme Court and physician-assisted suicide: rejecting assisted suicide but embracing euthanasia' (1997) 337(17) *New England Journal of Medicine* 1236, 1237.

141 Doctrine of double effect is not relied on to justify the withdrawal or withholding of artificial nutrition and hydration. S. Rys and others 'Continuous sedation until death: moral justifications of physicians and nurses – a content analysis of opinion pieces' (2013) 16 *Medicine, Health Care and Philosophy* 533; Orentlicher (above 140); Williams (note 61) 52 'Accordingly withdrawing food and water from a terminally sedated patient cannot be justified under the principles of double effect. It must and should always be confined to excluding situations involving withdrawing artificial nutrition and hydration.'

142 G. Miccinesi and others, 'Continuous deep sedation: physicians' experiences in six European countries' (2006) 31 *Journal of Pain and Symptom Management* 122, 122.

143 Ibid. 125.

food.¹⁴⁴ The rate at which treatment is withheld or withdrawn underlines the need to consider the impact ANH has on survival, particularly given the emotional, ethical, and legal aspects of patient care.

Two Cochrane Reviews and a literature review by Raijmakers et al. were discussed in Chapter 1. No clear position was identified in these reviews and Raijmakers et al. concluded that ‘little is known concerning the life-shortening or prolonging effect’¹⁴⁵ of artificial nutrition or artificial hydration. As such, the merits and demerits of this form of medical treatment are not entirely clear. The physiological impact of withdrawing ANH should therefore be assessed by looking beyond the circumstances in which palliative sedation without artificial nutrition and hydration is generally viewed as acceptable. In adopting this perspective, it is clear that a lack of hydration would eventually result in terminal dehydration and the death of the patient. Palliative sedation without ANH would therefore have a life shortening effect when the timeframe is such that it would result in terminal dehydration occurring.¹⁴⁶ There is no definitive time in which terminal dehydration will occur as this will be influenced by the condition of the patient at the time hydration is withdrawn. In effect, it could take hours or days, a week, two weeks, or longer for terminal dehydration to occur.¹⁴⁷ A review conducted by Broeckaert and Olarte illustrated that most patients who receive palliative sedation have a very short life-expectancy with the mean survival time of patients between 2.4 and 3.2 days after sedation is commenced.¹⁴⁸ The lack of hydration would therefore be unlikely to hasten their death as they will die due to their underlying illness.¹⁴⁹ In any case, terminal dehydration is not the only harm posed by ANH.

Finucane et al. examined the provision of artificial nutrition for patients with advanced dementia.¹⁵⁰ This was a comprehensive review as it identified and analysed data on MEDLINE from 1966 to March 1999 subject to certain limits.

- 144 P. Claessens and others, ‘Palliative sedation, not slow euthanasia: a prospective, longitudinal study of sedation in Flemish palliative care units’ (2011) 41(1) *Journal of Pain and Symptom Management* 14, 19.
- 145 N.J.H. Raijmakers and others, ‘Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects’ (2011) 22 *Annals of Oncology* 1478, 1485.
- 146 E. Delbeke, ‘The Legal Permissibility of Continuous Deep Sedation at the End of Life: A Comparison of Laws and a Proposal’ in S. Sterckx and others, *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013) 142.
- 147 Phillip Good and others, ‘Medically assisted hydration for adult palliative care patients’ (2014) 4 Cochrane Database of Systematic Reviews.
- 148 B. Broeckaert and J.M.N. Olarte, ‘Sedation in palliative care: facts and concepts’ in H. ten Have and D. Clark, *The Ethics of Palliative Care – European Perspectives* (Open University Press, 2002) 176.
- 149 Rys (note 103); N. Sykes and A. Thorns, ‘The use of opioids and sedatives at the end of life’ (2003) 4 *The Lancet Oncology* 312; R.M. Janssens and others, ‘Terminal sedation and dehydration go hand in hand’ (2005) 11(7) *International Journal of Palliative Nursing* 334.
- 150 T.E. Finucane and others, ‘Tube Feeding in Patients with Advanced Dementia’ (1999) 282(14) *Journal of the American Medical Association* 1365.

This research focused on the relevance of tube feeding for patients with dementia over a long period of their disease trajectory rather than focusing specifically on the end of life. Nonetheless, of particular relevance is data on survival as well as palliative effects of tube feeding. Issues identified with tube feeding included the possibility of causing death, e.g. 'Mortality during percutaneous endoscopic gastrostomy (PEG) tube placement ranges from 0% to 2% and perioperative mortality ranges from 6% to 24%.¹⁵¹ As to whether ANH had a palliative effect for patients with dementia, the published research suggested that tube feeding may in fact result in additional harm and burdens for the patient.¹⁵² In contrast to this, Sulmasy highlights two circumstances in which ANH might have a possible palliative role, namely in cases of bowel obstruction or terminal delirium.¹⁵³ An assessment of the potential benefits and harms of ANH will need to be carried out in each individual case. It would therefore be difficult to justify a policy of always providing or withdrawing treatment. Instead, the decision should be guided by patient autonomy, and what constitutes appropriate medical care in the circumstances.

2.3.2.1 Patient autonomy in the withholding and withdrawal of treatment

A first step for healthcare professionals in making decisions about ANH is to consult with the appropriate decision-maker.¹⁵⁴ There is a presumption that adult patients have capacity to make decisions concerning their own care. This right of self-determination stems from the concept of patient autonomy. Patient autonomy has an important role in defining treatment decisions in jurisdictions such as the US, UK, and Ireland. This not only encompasses decisions about curative treatment but also extends to decisions on palliative care, and treatment withdrawal. As people have a right to refuse treatment they can therefore refuse ANH.

There is no reason why treatment decisions about ANH should be made in a way which differs from other medical decisions. Patients at this stage of life are in a vulnerable position and should not be automatically excluded from such ethically

151 Ibid. 1366; M.A. Hull and others, 'Audit of outcome of long-term enteral nutrition by percutaneous endoscopic gastrostomy' (1993) 341 *Lancet* 869; L. Rabeneck and others, 'Long-term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes' (1996) 11 *Journal of General Internal Medicine* 287.

152 Delbeke (note 146); T. Morita and others, 'Association between hydration volume and symptoms in terminally ill cancer patients with abdominal malignancies' (2005) 16(4) *Annals of Oncology* 640.

153 D.P. Sulmasy, 'The Ethics of Medically Assisted Nutrition and Hydration at the End of Life: Separating the Wheat from the Chaff' in S.J. Youngner and R.M. Arnold, *The Oxford Handbook of Ethics at the End of Life* (Oxford University Press 2016) 138; R. B. Issaka and others, 'Palliative venting percutaneous endoscopic gastrostomy tube is safe and effective in patients with malignant obstruction' (2013) 28(5) *Surgical Endoscopy* 1669.

154 J.J. Fins and E.G. Nilson, 'Withholding and withdrawing life-sustaining care' in G. Hanks and others (eds), *Oxford Textbook of Palliative Medicine* (4th edn, Oxford University Press 2010) 320, 322 'When considering decisions regarding LST, the clinician needs to determine the appropriate decision-maker. For adult patients, the standing presumption is that the patient is capable of directing his or her own care.'

sensitive discussions. Fins and Nilson set out that ‘... it is the patient alone who will directly bear the physical and psychological burdens of an intervention. Because of these factors, the decision to start or continue life-sustaining interventions, *this negative right to be left alone*, should rest with the patient.’¹⁵⁵

Research by Rietjens et al. identified a failure to include patients in these decisions in the Netherlands. For instance, respondents discussed ANH in 34% of their recent cases while there was a request to forgo ANH made by the patient in 9% of recent cases.¹⁵⁶ It is notable that many physicians (23%) viewed the withholding of ANH as a given due to the administration of terminal sedation.¹⁵⁷ Although, this research was prior to the introduction of a Dutch national guideline on palliative sedation which will be examined in Chapter 5. Since then there has been greater patient involvement but also a substantial increase in treatment withdrawal. Patients’ capacity to make decisions about their healthcare will vary over the course of a serious illness. There will, of course, be occasions where the illness undermines their ability to make a decision. Accordingly, in 37% of cases there was no discussion due to the patient’s lack of capacity.¹⁵⁸ This is a considerable failing not just for patient autonomy, but for the delivery of appropriate palliative care. It can be seen as a lost opportunity to engage with the patient on the subject of ANH. The right of autonomy will be discussed in the next chapter but this issue hints at the need for much earlier and proactive engagement on the part of the healthcare professional. In such circumstances where the patient lacks the capacity to make a contemporaneous decision they may have provided for their wishes through use of an advance healthcare directive. It is unlikely that many advance healthcare directives would be as specific to address the issue of ANH and palliative sedation. Consequently, an assessment of the patient’s best interests will be needed in specialist palliative care.

2.3.2.2 *The best interests assessment*

The manner in which the withdrawal of ANH is justified is of particular importance as the failure to provide nutrition and hydration may result in a murder charge.¹⁵⁹ The elements of the offence of murder were set out in the second section of this chapter. The ‘building blocks’¹⁶⁰ of a charge are the actus reus and mens rea. The actus reus may be performed by an action or an omission based on the circumstances. An act has been described as ‘events or states of affairs for which a person might be responsible according to the principles of responsibility that guide such judgments.’¹⁶¹ In general, liability does not attach in situations where a person

155 Ibid. 320 emphasis in original.

156 Rietjens (note 101) 180.

157 Ibid.

158 Ibid.

159 *R v Gibbins and Proctor* (1918) 13 Cr App R 134, *R v Stone and Dobinson* [1977] QB 354.

160 L. Campbell and others, *Criminal Law in Ireland: Cases and Commentary* (Clarus Press 2010) 80.

161 H. Gross, *A Theory of Criminal Justice* (Oxford University Press 1979) 56.

fails to act unless there is a legal duty to do so. The withdrawal of ANH has been considered an omission by the courts, and its withdrawal could therefore meet the actus reus requirement if a legal duty exists to provide it.¹⁶² Such a duty arises in the relationship between healthcare professional and patient.¹⁶³ As a result, a doctor or nurse might satisfy the actus reus requirement unless it could be shown that the withdrawal of treatment was in the patient's best interests. This is the line of reasoning which was taken in *Airedale N.H.S. v Bland*¹⁶⁴ and in Ireland in *Re a Ward of Court*.¹⁶⁵

In *Airedale N.H.S. v Bland*, Tony Bland had been in a persistent vegetative state for three years and was reliant on life support. Healthcare professionals responsible for the care of Tony Bland were of the opinion that 'no useful purpose was to be served by continuing that medical care and that it was appropriate to stop the artificial feeding and other measures aimed at prolonging his existence.'¹⁶⁶ In order to clarify the legality of terminating ventilation and withdrawing ANH the hospital sought clarification from the court. At first instance, the Court held that it was in the best interests of the patient that the medical treatment be withdrawn. This decision was appealed by the Official Solicitor acting on behalf of Tony Bland. The decision at first instance was affirmed by the Court of Appeal and was again appealed by the Official Solicitor.

The general issue before the House of Lords was described as follows, 'In what circumstances, if ever, can those having a duty to feed an invalid lawfully stop doing so?'¹⁶⁷ In particular, can an attending physician 'lawfully discontinue all life-sustaining treatment and medical supportive measures designed to keep the defendant alive in his existing persistent vegetative state'?¹⁶⁸ The Court questioned whether ANH amounted to medical treatment or medical care. The next step was to consider whether the removal of ANH was an act or an omission. As doctors and nurses owe a duty of care, an omission can amount to the actus reus.¹⁶⁹ This situation was avoided as there is no duty to provide treatment which is not in the best interests of the patient. The treatment was viewed as 'futile',¹⁷⁰

162 Williams (note 121) 62 'As has been seen, omissions liability is based on a prerequisite duty (and thus can be avoided in the absence of that duty), whereas liability in the case of acts is simply based on the sanctity of life (Elkington 1968: 744)'.

163 *Barnett v Chelsea and Kensington Hospital Management Committee* [1969] 1 QB 428.

164 *Airedale N.H.S. v Bland* [1993] AC 789, [1993] 2 WLR 350.

165 *Ward of Court (withholding medical treatment)* (No 2), *Re*, [1995] IESC 1, [1996] 2 IR 73, [1996] 2 IR 79, [1995] 2 ILRM 401.

166 *Airedale N.H.S. v Bland* [1993] AC 789, 856.

167 *Ibid.* 857.

168 *Ibid.* 856.

169 H. Biggs, 'Euthanasia and death with dignity: still poised on the fulcrum of homicide' (1996) *Criminal Law Review* 878, 882 'In Bland the proposed withdrawal of treatment was defined as an omission; accordingly it would only form the actus reus of homicide if there existed a duty to continue to treat this patient.'

170 *Airedale N.H.S. v Bland* [1993] AC 789, 837; Beauchamp (note 78) 169 'Physicians have no obligation to provide pointless, futile, or contradicted treatment.'

had no ‘affirmative benefit’,¹⁷¹ and ‘no longer fulfils any therapeutic purpose.’¹⁷² Consequently, there would be no criminal liability incurred by withdrawing his treatment.¹⁷³ This was described by Williams as, ‘the *only* method by which the doctors could be found to have acted lawfully.’¹⁷⁴ Williams went on to state that the judgement ‘only relied upon the AOD because it “existed” certainly there is no expression of confidence in the AOD as the foundation of treatment withdrawal cases.’¹⁷⁵ In a similar manner, Jackson described the approach taken in this case as ‘backwards reasoning’ through which a judge determines the preferred outcome, and then identifies a line of legal reasoning which facilitates this result.¹⁷⁶ Nevertheless, this approach has been relied on by courts in subsequent decisions on the withdrawal of ANH.¹⁷⁷

In Ireland, the question of withdrawing ANH arose in *Re a Ward of Court*. In the High Court, Lynch J held that the ANH could be withdrawn from the ward. This decision was appealed to the Supreme Court which upheld the High Court’s decision by a 4:1 majority. The Court adopted the line of reasoning which had been set out in *Airedale NHS v Bland*. These cases highlight several issues which should be considered in greater detail. These are the categorisation of ANH as medical treatment, the argument that withdrawal constitutes an omission, and the distinction, if any, between withholding and withdrawing treatment.

ARTIFICIAL NUTRITION AND HYDRATION AS MEDICAL TREATMENT OR CARE?

The provision of nutrition and hydration has a compelling emotional dimension. It signals a way of caring and providing for a person. This emotional factor adds to the legal and ethical concerns which shape the treatment decision.¹⁷⁸ Patients at

171 *Airedale N.H.S. v Bland* [1993] AC 789, 884.

172 Ibid. 873. – Lord Goff – ‘If the question is asked, as in my opinion, it should be, whether it is in his best interests that treatment which has the effect of artificially prolonging his life should be continued, the question can sensibly be answered to the effect that his best interests no longer require that it should be.’

173 G. Williams, ‘Acts and omissions in treatment withdrawal: conceptual problems and policy decisions’ (2008) 39 *Cambrian Law Review* 75, 78

174 Ibid 80 (emphasis in original).

175 Ibid 78. AOD stands for acts and omissions distinction; Williams highlights that there are policy reasons which support the use of this line of reasoning in allowing the medical practitioner to withdraw artificial nutrition and hydration from the patient.

176 E. Jackson and J. Keown, *Debating Euthanasia* (Hart Publishing 2012) 26.

177 *W Healthcare NHS Trust v KH*, [2004] WLR 834, patient not in a persistent vegetative state; *Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403; *Swindon and Marlborough NHS Trust v S* [1995] 3 Medical Law Review 84; *An NHS Trust v M* [2001] 2 FLR 367; *An NHS Trust v H* [2001] 2 FLR 501; *In re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2011] EWHC 2443 (Fam), [2012] 1 WLR 1653; *W(by her litigation friend B) v M(by her litigation friend, the Official Solicitor) and S and A NHS Primary Care Trust* [2011] EWHC 2443 (Fam).

178 Sulmasy (note 153) 135 ‘The comfort and concern symbolized by providing food and water are sometimes offered as reasons morally necessitating medical interventions to provide nutrition and hydration when patients are unable to eat.’

the end of life generally eat and drink less.¹⁷⁹ In such circumstances, artificial hydration is not normally commenced. However, people close to the patient may feel an obligation to provide hydration and nutritional support. The nature of ANH is such that these practices do not effectively provide 'the symbolic comfort' which people may wish to provide.¹⁸⁰ As Sulmasy noted, '[p]atients fed by vein or enterally placed tubes do not experience the pleasure of taste and do not experience the human interaction that surrounds a human meal.'¹⁸¹ The emotional aspect of the practice is therefore predominantly an issue for the healthcare professional and is unlikely to significantly alter the experience of the sedated patient. Nevertheless, viewing ANH through an emotional lens creates an appearance of care. In reality, the practice is conceived of as a medical treatment rather than medical care, thereby allowing for withdrawal if it is not in the best interests of the patient. This point is illustrated by the cases cited in the preceding paragraphs.¹⁸²

In *Re a Ward of Court* ANH was administered by way of a nasogastric tube and this was seen as being 'intrusive'¹⁸³ and as constituting 'an interference with the integrity of her body and cannot be regarded as normal means of nourishment.'¹⁸⁴ This reasoning was supported by reliance on the US case, *Cruzan v Director Missouri Department of Health*.¹⁸⁵ In *Cruzan* Brennan J commented that 'The artificial delivery of nutrition and hydration is undoubtedly medical treatment.'¹⁸⁶ Despite this, in *Re a Ward of Court* it was argued for the institution that ANH was merely 'the equivalent of food and drink which everybody required for survival'¹⁸⁷ and the nasogastric tube had become normal due to its duration.¹⁸⁸ Both the High Court and the Supreme Court in *Re a Ward of Court* were of the opinion that ANH constituted a form of medical treatment rather than medical care. As such, once the treatment was withdrawn the patient would die from her original injuries rather than lack of food and water.

Distinctions of such importance will attract criticism in any such case. The line between what constitutes medical treatment or medical care has been described by Beauchamp and Childress as 'unacceptably vague'.¹⁸⁹ However, Sulmasy puts the distinction in relief by stating:

179 ten Have (note 117) 131.

180 Sulmasy (note 153) 135.

181 Ibid.

182 See also M.A. Ashby and D. Mendelson, 'Gardner; re BWV: Victorian Supreme Court makes landmark Australian ruling on tube feeding' (2004) 181(8) *Medical Journal of Australia* 442.

183 *Ward of Court (withholding medical treatment)* (No 2), *Re*, [1996] 2 IR 79, 124.

184 Ibid. 125.

185 *Cruzan v Director Missouri Department of Health* (1990) 497 US 261.

186 Ibid. 307.

187 *Ward of Court (withholding medical treatment)* (No 2), *Re*, [1996] 2 IR 79, 143.

188 Ibid. 143.

189 Beauchamp (note 78) 162 'Unfortunately, neither a long history nor precedent guarantees clarity or adequacy. The distinction between ordinary and extraordinary means of treatment is unacceptably vague and morally misleading.'

No one without a medical license is permitted to insert a PEG tube or a subclavian vein catheter for TPN. Whereas providing food and beverage for normal eating and drinking can be counted as basic care (and food and water ought always to be *offered* to patients), the medical modalities for providing nutrition and hydration are absolutely not the same, experientially or mechanically, as eating and drinking.¹⁹⁰

Similarly, Mason and Laurie stated that ‘any form of feeding which requires some *medical* training and expertise can be considered medical treatment’.¹⁹¹ A clear dividing line therefore exists between treatment and care.¹⁹²

AN ACT OR AN OMISSION?

The distinction between acts and omissions has attracted a considerable amount of criticism,¹⁹³ and it has been described as ‘more of a hindrance than an aid to resolving the legal problems in this area.’¹⁹⁴ Defining treatment withdrawal as an act or an omission leads to an examination of the minutiae of the practice. Each element is analysed and categorised according to the associated physicality in an attempt to define legal and ethical permissibility. It is a process which often results in conflicting arguments. Jackson examined the distinction between acts and omissions in the context of treatment withdrawal, and argued that ‘the differences between the two sorts of conduct, while not non-existent, are in this case insufficient to bear the moral weight that is placed upon them by the law.’¹⁹⁵ All of this suggests that specialist palliative care requires a legal framework with a more robust foundation in order to ensure that healthcare professionals and patients have certainty about the limits of care and the type of care which can be provided.

A DISTINCTION BETWEEN WITHHOLDING AND WITHDRAWING ARTIFICIAL NUTRITION AND HYDRATION?

There is no additional legal justification required for the withdrawal of treatment as compared with the withholding of treatment.¹⁹⁶ Each decision should be

190 Sulmasy (note 153) 136–137.

191 J.K. Mason and G. Laurie, *Mason & McCall Smith's Law & Medical Ethics* (8th edn, Oxford University Press 2011) 576 (emphasis in original).

192 Sulmasy (note 153) 137 ‘There is no reason to think that being nourished through a tube forcing food into one’s stomach is morally or medically different from being ventilated through a tube forcing air into one’s lungs.’

193 J. Rachels, ‘Active and passive euthanasia’ (1975) 292 *New England Journal of Medicine* 78; H. Kuhse, *The Sanctity-of-Life Doctrine in Medicine: A Critique* (Oxford University Press 1987) 38; Begley (note 80) 865.

194 P. Hanafin, *Last Rights: Death, Dying and the Law in Ireland* (Cork University Press 1997) 24.

195 Jackson (note 176) 30.

196 Sulmasy (note 153) 141 ‘It is a standard teaching in bioethics that withdrawing a medical intervention does not require more moral justification than withholding that

approached from the perspective of whether the treatment would be effective for the patient, and whether it would constitute an unreasonable burden for the patient. Nonetheless, the withdrawal of treatment may be perceived as more ethically or emotionally significant than the decision not to commence ANH.¹⁹⁷ There may be a greater moral weight when treatment is discontinued as compared with situations where it was never commenced. This underlines the importance of legal clarity around this decision as healthcare professionals may be discouraged from ever providing treatment in order to avoid subsequent complex decisions about withdrawal.

The cultural and religious beliefs of the patient also have an important role. There are some religions which recognise a distinction between withholding and withdrawing treatment, among these are Jewish groups. As Schostak notes 'both legally and ethically, there is no distinction between withholding or withdrawing medical treatment. In halacha, however, the difference between the two is extremely significant.'¹⁹⁸ Naturally, members of the Jewish faith may hold contrasting personal views on this point. It follows that the practice of withholding and withdrawing treatment is not accepted across all jurisdictions and faiths.¹⁹⁹ It is therefore important that the legal framework reflects such perspectives while still providing clarity for the healthcare professional and patient.

2.4 Conclusion

This chapter set out to examine the legitimacy of the distinction between specialist palliative care practices and euthanasia. In drawing out this distinction, the legal

intervention.'; D.N. Ko and C.D. Blinderman, 'Withholding and withdrawing life-sustaining treatment (including artificial nutrition and hydration)' in N. Cherny and others (eds) *Oxford Textbook of Palliative Medicine* (5th edn, Oxford University Press 2015).

197 Fins (note 154) 324 'Although the ethics literature asserts that there is no ethical distinction between withholding and the withdrawal of LST, it can be emotionally more difficult to withdraw life-sustaining therapy than not to initiate it.'; Sulmasy (note 153) 142–143 'People seem to feel more causally responsible if they discontinue a treatment than if they never started it in the first place, even if they cannot articulate a rational reason for that intuition.'; O. Lesieur and others, 'Withholding or withdrawal of treatment under French rules: a study performed in 43 intensive care units' (2015) 5 *Annals of Intensive Care* 15 'Contrary to ethicists, many intensivists clearly distinguish between withholding and withdrawal decisions, with the former being perceived as more "passive".'

198 Z. Schostak, 'Jewish ethical guidelines for resuscitation and artificial nutrition and hydration of the dying elderly' (1994) 20 *Journal of Medical Ethics* 93 cited by Sulmasy (note 153) 142; E.L. Krakauer and T.E. Quinn, 'Sedation in palliative medicine' in G. Hanks and others (eds) *Oxford Textbook of Palliative Medicine* (4th edn, Oxford University Press 2011) 1562 'Religious and cultural beliefs should be explored as carefully as possible and every effort made to assure that palliative sedation or any proposed treatment is compatible with cherished beliefs and values of the patient.'

199 Ko (note 196); R.H. Blank, 'End-of-life decision making across cultures' (2011) 39 *Journal of Law, Medicine and Ethics* 201.

framework for euthanasia in the Netherlands was discussed, the concept of intention was set out, and legal and ethical justifications were examined. The section on the Netherlands highlighted the points of similarity between the practices. However, it is recognised that this is just one jurisdiction and other similarities or differences may exist if the comparison was based on a different legal system. In any case, a clear resemblance is evident between ‘lasting and unbearable suffering’ and the concept of refractory suffering. This underlines the importance of a clear legal framework which distinguishes and clarifies the boundaries between these practices. In this respect, it is suggested that a distinction solely based on the doctrine of double effect is inadequate. Double effect can provide an ethical justification depending on the interpretation but it is poorly defined in case law to date. Moreover, as was noted in the body of the chapter, it is inappropriate for specialist palliative care practices to be guided by an ethical justification. Such an approach leads to inconsistency between providers of palliative care and impacts negatively on the care received by the patient.

This chapter also illustrated the complexity of palliative sedation without artificial nutrition and hydration. The withholding or withdrawal of treatment can be justified based on patient autonomy or an assessment of best interests. The decision is one which should not be made automatically upon the administration of palliative sedation. Instead, decisions on ANH should be made on a case-by-case basis depending on the wishes and medical condition of the patient.

In sum, the legal framework for palliative care must deliver on several points. It must provide a clear legal distinction between euthanasia and specialist palliative care practices, it must protect the human rights of the patient, and it must respond to broader debates about end-of-life care. As ever more jurisdictions move to liberalise laws on euthanasia it will become increasingly important that palliative care has an established legal framework which can limit potential abuses and provide clarity for both the healthcare professional and the patient. Uncertainty does not benefit the level of care provided and it can lead to undertreatment as well as overtreatment of the patient; neither of which advance the goals of palliative care.²⁰⁰

200 S. Anderson Fohr, ‘The Double Effect of Pain Medication: Separating Myth from Reality’ (1998) 1(4) *Journal of Palliative Medicine* 315, 319 A lack of clarity on the sedation of a patient could be seen as ‘a major cause of under treatment of cancer pain.’; Beauchamp (note 78) 160 ‘Giving priority to withholding over withdrawing treatment can lead to overtreatment in some cases, that is, the continuation of no longer beneficial or desirable treatment for the patient. Less obviously, the distinction can lead to undertreatment. Patients and families worry about being trapped by biomedical technology that, once begun, cannot be stopped.’

3 The human rights framework for palliative care

3.0 Introduction

Human rights have a fundamental role in shaping the care and treatment provided to the patient at the end of life. Previous chapters have highlighted human rights concerns such as the need to respect the dignity of the terminally ill patient, access to appropriate palliative care, participation in decision-making, and equality of palliative care provision across different institutions. Palliative care therefore engages human rights such as the right to health, the right to bodily integrity, protection from inhuman or degrading treatment, the right of autonomy, the right of equality, and the right to family life.¹ This chapter considers the influence of these rights in promoting central elements of palliative care and shaping healthcare decision-making in practice. It therefore avoids a myopic perspective which concentrates solely on the act of administering sedation but instead takes account of the broader framework in which care is provided. In particular, this chapter examines the role of the ethical and legal concepts of autonomy and dignity in defining and enhancing the provision of palliative care. The chapter will also examine the substance of the right to palliative care. On this point, it will be argued that this right can often be reduced to a right to pain management and can rarely be relied on by the patient in their individual circumstances. Consequently, rights such as the right to bodily integrity and protection from inhuman or degrading treatment may prove more effective in promoting a high quality of palliative care.

The ethical concept and legal recognition of autonomy will be explored in the first section of this chapter. This will examine the limits of autonomy and demonstrates the challenge of fully integrating the traditional liberal conception of autonomy in palliative care. Autonomy is significant in determining the legal status of palliative sedation and the withholding and withdrawal of treatment. However, there are situations where the patient will lack capacity and it will be necessary to draw on a broader human rights framework to provide clarity on the medical treatment and care to be pursued. On this basis, the second section in this chapter

1 Parliamentary Assembly, 'Palliative care: a model for innovative health and social policies' Resolution 1649 (2009) adopted on 28 January 2009 [14].

will turn to consider the concept of dignity along with the right to physical integrity, and protection from inhuman or degrading treatment. The third section in this chapter examines the arguments for a right to palliative care. The content of this right will be discussed and it will be argued that recognising such a right is unlikely to affect substantial change for the individual patient due to existing rights protection. It must be noted at the outset that this chapter will address only a small aspect of the human rights issues in palliative care. It would require a separate work to explore fully the human rights implications arising at the end-of-life and to address not only the rights of patients but to also include the rights of family members and healthcare practitioners. Regardless, human rights serve an important function in establishing a minimum standard of care as well as defining the limits of practice. A human rights discourse can also enrich advocacy at national and international levels thereby promoting the extension of palliative care to a greater number of vulnerable and marginalised groups in society.

3.1 Defining the concept of autonomy

The term autonomy is derived from the Greek words ‘autos’ meaning self and ‘nomos’ meaning rule or law.² Autonomy is a pre-eminent concept in medical ethics and, accordingly, has a central role in healthcare decision-making. It has been drawn upon in a multitude of cases which raise questions concerning the end of life. These include treatment withdrawal decisions,³ arguments for the legalisation of assisted suicide,⁴ and demands for the provision of medical treatment.⁵ These cases illustrate how a patient’s healthcare preferences represent a subjective assessment of treatment options and reflect personal values. The status of this concept in the United Kingdom and Ireland is such that it is easy to perceive it as being universally accepted and actively promoted. Not all countries privilege autonomy in this way and countries such as France have proven more cautious in promoting patient autonomy. Furthermore, the concept of autonomy is subject to differing interpretations both in theory and by the courts. It is therefore difficult to adequately define autonomy due to the range of competing definitions.⁶ Nonetheless, it is a concept which is closely tied to ideas of self-governance and self-determination.

2 J.T. Pring, *The Oxford Dictionary of Modern Greek: Greek–English and English–Greek* (Doubleday 1986) [self:] 281; *ibid.* [law] 180.

3 *Ward of Court (withholding medical treatment)* (No 2), *Re*, [1996] 2 IR 73.

4 *Pretty v United Kingdom* (2002) 35 EHRR 1.

5 *Burke, R (on the application of) v The General Medical Council* [2004] EWHC 1879 (Admin).

6 B.A. Garner, *Black’s Law Dictionary* (9th edn, Thompson/West 2009) 154 ‘An individual’s capacity for self-determination.’; R. Lindley, *Autonomy* (MacMillan Education 1986) 6 ‘An autonomous person has a will of her or his own, and is able to act in pursuit of self-chosen goals.’; O. O’Neill, *Autonomy and Trust in Bioethics* (Cambridge University Press 2002) 22 ‘self-mastery; choosing freely; choosing one’s own moral position and accepting responsibility for one’s choice’.

The right of autonomy was described by Buchanan and Brock as protecting an individual's 'interest in making significant decisions about his or her own life'.⁷ The work of John Stuart Mill is regularly drawn on in discussion of autonomy. In this respect, the concept of autonomy is reflected in the line, '[o]ver himself, over his own body and mind, the individual is sovereign'.⁸ Overall, autonomy has a significant role in ensuring appropriate palliative care is provided to the patient.⁹ This is based on more than the subjective nature of pain.

3.1.1. The role of autonomy in advancing palliative care goals

The World Health Organization definition of palliative care was quoted in the Introduction to this work. It set out that 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.¹⁰

Key goals emerging from this definition are the quality of life for patients and their families, and the relief of suffering.¹¹

Various attempts have been made to define 'quality of life' in the context of palliative care but it is a concept which lacks precision. It can be assigned distinct meanings based on the underlying illness and the practical support measures available to the patient.¹² However, it can also be informed by the input of the patient who defines the concept on a subjective basis. Each patient will emphasise different factors and goals that underpin their unique conception of the quality of life.¹³

In a similar manner, the relief of suffering can be more accurately addressed through discussion with the patient. As outlined in earlier chapters, the nature of

7 A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press 1989) 36.

8 J.S. Mill, *On Liberty* (JW Parker and Son 1859) 22.

9 F. Wilson and others, 'Autonomy and choice in palliative care: time for a new model?' (2014) 70(5) *Journal of Advanced Nursing* 1020, 1021.

10 C. Sepúlveda and others, 'Palliative care: the World Health Organization's global perspective' (2002) 24(2) *Journal of Pain and Symptom Management* 91, 94.

11 L. Radbruch and others, 'White Paper on standards and norms for hospice and palliative care in Europe: part 1' (2009) 16(6) *European Journal of Palliative Care* 278; D. Clark and others, 'Conceptual Tensions in European Palliative Care' in D. ten Have and D. Clark, (eds) *The Ethics of Palliative Care: European Perspectives* (Oxford University Press 2002) 52.

12 S. Kaasa and J.H. Loge, 'Quality of life in palliative care: principles and practice' (2003) 17(1) *Palliative Medicine* 11, 12 'QOL may have different meanings to different people.'

13 Radbruch (note 11) 283 'However, the meaning of "quality of life" can only be determined by each palliative care patient individually for themselves.'

suffering may go beyond the physical and encompass psychological or existential distress. Not all suffering can be treated on a pharmacological basis and it is therefore important for healthcare professionals in palliative care to fully engage with the patient in order to understand their experience. The centrality of patient autonomy and self-determination goes back to Elisabeth Kübler-Ross and the origins of modern palliative care. It is necessary to engage with the experience of the individual and to ensure they are not silenced at the end-of-life.

The status of autonomy in palliative care has been underlined by the European Association of Palliative Care (EAPC). In a 2003 paper on the relationship of euthanasia to palliative care it was stated that '[r]espect for autonomy is an important goal of palliative care which seeks to strengthen and restore autonomy and not to destroy it.'¹⁴ Traditionally, there was a pronounced opposition between palliative care and euthanasia. Claims for euthanasia were often based on patient autonomy. This placed palliative care in a difficult position as it raised questions about the extent to which autonomy was respected. The opposition between the practices has softened in parts as demonstrated by jurisdictions such as Belgium.¹⁵ In the context of this work, it is suggested that both palliative medicine and euthanasia can be accommodated in a jurisdiction and this does not mean that palliative medicine is failing. Instead, it is a recognition of the diverse needs and judgements made by individuals. Regardless, it is important that the voice of the patient be heard and that the boundaries between the practices are clearly defined for all. In a more recent EAPC paper on the standards and norms for palliative care in Europe it was set out that '[i]n palliative care, the intrinsic value of each person as an autonomous and unique individual is acknowledged and respected. ... Ideally, the patient preserves his/her self-determination regarding the power of decision on place of care, treatment options and access to specialist palliative care.'¹⁶ The reference to 'ideally' suggests that the patient will not always preserve their self-determination and that there may be instances where their autonomy is constrained. Autonomy may be limited due to a lack of capacity but there are other ways in which an autonomous decision could be limited. On this point, it is important to reflect on the ethical concept of autonomy and to draw out shortcomings which challenge the achievement of the palliative care goals noted above.

3.1.2 The liberal conception of autonomy in palliative care

The traditional liberal conception of autonomy is most closely associated with the work of John Stuart Mill.¹⁷ Mill adopted an approach which stemmed from a utilitarian perspective. According to Mill, respect for autonomy brings about more

14 L.J. Materstvedt and others, 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force' (2003) 17 *Palliative Medicine* 97, 98.

15 D.A. Jones and others (eds), *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge University Press 2017).

16 Radbruch (note 11) 283.

17 Mill (note 8).

good than evil. Therefore, an individual's autonomy should be respected due to the benefits which it can bring about for the individual and society.¹⁸ A person should be permitted to act according to their own beliefs and values, regardless of how they might be perceived by other people. Although this is not to suggest that autonomy is not subject to any limits. In circumstances where harm could be caused to another person then an interference with a person's autonomy will be justified. For instance, 'the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant.'¹⁹ In the context of healthcare, the liberal conception of autonomy led Dworkin to state that '[w]e allow someone to choose death over radical amputation or a blood transfusion, if that is his informed wish, because we acknowledge his right to a life structured by his own values'.²⁰

Donnelly highlighted that the liberal conception of autonomy is more nuanced than being solely about non-interference with the individual.²¹ Nonetheless, the liberal conception of autonomy does not fully contribute to realising the goals of palliative care. This becomes clear when we consider the normative critiques of autonomy which focus on the moral status of the individual, the impact on other values, and the limited contribution of autonomy.²² This discussion highlights the importance of clarity in the promotion of autonomy for palliative care. Vague appeals to the importance of autonomy contribute little if the concept is not subsequently defined and expanded upon.

The liberal conception of autonomy has been criticised for not affording sufficient weight to relationships between people and instead isolating the individual. This detached perspective has been criticised by Callahan who argued that '[Autonomy] buys our freedom to be ourselves, and to be free of undue influence by others, at too high a price. It establishes contractual relationships as the principal and highest form of relationships. It elevates isolation and separation as the necessary starting point of human commitments.'²³ There is little recognition of the broader factors which inform and shape how a decision is ultimately made. It is a perspective which is devoid of recognition for obligations and duties which are shared between people. In short, the liberal view of autonomy fails to capture 'the normative consequences of social embeddedness.'²⁴ Decisions taken in palliative care are not isolated from other factors but are shaped by commitments and concern for other people. As noted above, among the goals of palliative care is

18 Ibid. 207.

19 Ibid. 22.

20 R. Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (Harper Collins 1993) 224.

21 M. Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2011) 22.

22 Ibid. 33.

23 D. Callahan, 'Autonomy: a moral good, not a moral obsession' (1984) 14(5) *Hastings Center Report* 40, 41.

24 Donnelly (note 21) 34.

the improvement of the quality of life for patients and their families. The need to take account of the support required for a patient's family is addressed in Chapter 5 in the context of the KNMG Guideline for Palliative Sedation. These relationships are neglected in a strict liberal conception of autonomy yet are fundamental in the provision of appropriate palliative care. For instance, it was highlighted in Chapter 1 that one of the locations where patients may receive palliative care is in the home. In order to achieve this, it would require the agreement of family members. Such decisions cannot be made on a unilateral basis given the potential consequences. For instance, a person nearing the end-of-life may insist on being cared for at home, but the availability of support services or lack thereof, may place an undue burden on family members. This could in turn be detrimental to the family's physical and/or mental wellbeing.

The second normative critique of the liberal conception of autonomy is the effect on other values and the impact on trust. Again, the liberal view of autonomy underlines the distinct nature of the individual and their independence from others. On this point, O'Neill suggested that 'Trust flourishes between those who are linked to one another; individual autonomy flourishes where everyone has "space" to do their own thing'.²⁵ It follows that the liberal conception of autonomy would be expected to have a negative impact on trust in the patient–doctor relationship. A study by Hamano et al. demonstrated the importance of trust in contributing to the quality of death for the patient receiving palliative care.²⁶ Consequently, trust must be protected as far as possible. In any case, research suggests that trust in the medical profession is not so easily diminished. On this point, Donnelly stated that 'the apparent resilience of the relationship between medical professionals and patients does suggest that the threat of autonomy to patient trust in the medical profession may be overstated'.²⁷

The third normative critique of autonomy is that it is 'intellectually and practically limited in what it offers',²⁸ It can often be reduced to a right to refuse or consent to medical treatment, and a duty for healthcare professionals not to administer treatment in the absence of patient consent.²⁹ This does not encourage the provision of information to the patient. The effect is that the patient makes a decision within a framework of options which are constructed by the healthcare professional. Donnelly summarised the situation as follows: 'it does not require the provision of alternatives. Nor does the traditional view of autonomy require efforts to educate (within the limited context of the particular decision to be made) or engage with the patient, to create a space for her to make the decision which best serves her needs'.³⁰

25 Ibid. 36.

26 J. Hamano and others, 'Trust in physicians, continuity and coordination of care, and quality of death in patients with advanced cancer' (2017) *Journal of Palliative Medicine* [ahead of print].

27 Donnelly (note 21) 38.

28 Ibid. 39.

29 Ibid.; O'Neill, (note 6) 37.

30 Donnelly (note 21) 39–49.

To achieve the goals of palliative care, as outlined above, it is suggested that a richer interpretation of autonomy is required which reflects the social relations and embedded nature of the individual. In drawing on the concept of autonomy it is therefore important to be clear on what is meant by this concept and how it is to be promoted in practice. Unfortunately, it is beyond the scope of this work to engage in sustained discussion about what that precise form of autonomy should be. Arguments have been advanced that a communitarian model of autonomy should be adopted which draws on common values and relationships.³¹ There is a strong argument to be made for the contribution of relational autonomy as it has previously been suggested that autonomy is essentially a relational practice.³² This would push the conception of autonomy beyond a representation of socially-isolated individualism. Wilson et al. have argued for a conception of autonomy which is based on a 'decision ecology' model.³³ Significantly, this is an approach which 'acknowledges the wider social context, individual narratives and emphasises trust between professionals and patients [to] support healthcare decision-making at end of life',³⁴ In addition, Donnelly outlined a view of autonomy as empowerment.³⁵ This is developed through reference to relational theorists as well as the work of Raz.³⁶ A common feature of these formulations of autonomy is that they look beyond individualism and take account of the socially embedded nature of the individual. In this context, autonomy is not simply about non-interference but instead it is about encouraging greater patient involvement with an awareness of the internal and external factors which can limit a person's agency. Palliative care must actively engage with these wider considerations due to the broad remit of palliative care and the variety of locations in which care can be provided. Although there are challenges in defining the ethical concept of autonomy this does not diminish its status or the importance of how autonomy is protected by the law.³⁷

3.1.3 Patient autonomy and the law

The ethical concept that is autonomy has been recognised and protected in common law,³⁸ Irish constitutional provisions,³⁹ the European Convention on Human Rights,⁴⁰

31 Wilson (note 9); S. Woods, *Death's Dominion: Ethics at the End of Life* (Open University Press 2007).

32 P. Schotsmans, 'Palliative Care: A Relational Approach' in H. ten Have and D. Clark (eds) *The Ethics of Palliative Care: European Perspectives* (Oxford University Press 2002).

33 Wilson (note 9).

34 Wilson (note 9) 70.

35 Donnelly (note 21) 41.

36 J. Raz, *The Morality of Freedom* (Oxford University Press 1979).

37 Donnelly (note 21) 41.

38 *Re T (Adult: Refusal of Medical Treatment)* [1992] 3 WLR 782.

39 Bunreacht na hÉireann, Article 40.3.1°.

40 European Court of Human Rights, Article 8; Human Rights Act 1998; General Medical Council, 'Treatment and care towards the end of life: Good practice in decision making' (2010) [9] 'If you are involved in decisions about treatment and care

and the Charter of Fundamental Rights.⁴¹ Autonomy can give rise to both negative and positive obligations and the treatment of these obligations in case law will be outlined in this section. Among the points to be considered is whether a patient could actively request palliative sedation at the end-of-life and whether such a request would be respected. Prior to this it can be noted that the right of autonomy is most often exercised in the context of consent to medical treatment. For consent to be effective the patient must have sufficient capacity and should be informed about the nature and consequences of the medical treatment.⁴²

The importance of consent in medical treatment was highlighted in *Re a Ward of Court*. Denham J set out that this emerges from civil, criminal, and constitutional law. The absence of consent to medical treatment may result in ‘trespass against the person in civil law, a battery in criminal law, and a breach of the individual’s constitutional rights’,⁴³ Patient consent is therefore an essential aspect of treatment and, from a legal perspective, should not be dispensed with solely because the patient is in a vulnerable condition.

Legal and ethical justifications for specialist palliative care practices were discussed in the previous chapter. The concept of consent was not raised in discussion of double effect. Instead, the focus was on the intention of the healthcare professional. Yet, the importance of informed consent was recognised in *Vacco v Quill* where it was submitted that ‘the concept of sedating pharmacotherapy is based on informed consent and the principle of double effect’,⁴⁴

Patient consent for palliative sedation raises several concerns for healthcare professionals. These include fears that seeking informed consent would be an additional burden for the patient, it may result in anxiety, or there can be broader concerns about family members understanding of palliative sedation.⁴⁵ In addition to this, consent may be problematic due to difficulties in communicating with the patient near the end-of-life. This could be due to physical or emotional challenges in communication. Dwyer and McCarthy noted that in a study of nurses in a hospice setting that ‘[m]any of the participants acknowledged that the dying process itself made honest communication difficult and they suggested that it was important to be sensitive and careful in terms of what is said to both patients and relatives, in the best interest of the patient.’⁴⁶ The importance of informed consent

towards the end of life, you must be aware of the *Human Rights Act 1998* and its main provisions, as your decisions are likely to engage the basic rights and principles set out in the Act.’

41 Charter of Fundamental Rights of the European Union, Article 7.

42 S.W. Chan, ‘Montgomery and informed consent: where are we now?’ (2017) *British Medical Journal* 357.

43 *Ward of Court*, [1996] 2 IR 79, 156.

44 *Vacco v Quill* (1997) 521 U.S. 793, 808.

45 A. Dean and B. Beard, ‘Is sedation at the end of life compatible with the principles of palliative care?’ (2015) 5 *End of Life Care Journal* e000001; I. Dwyer and J. McCarthy, ‘Experiences of palliative care nurses in the utilisation of palliative sedation in a hospice setting’ (2016) 6 *End of Life Journal* e000015.

46 Dwyer (note 45) 4.

has been widely acknowledged by healthcare professionals but consent may not always be possible due to cognitive impairments at the end-of-life.⁴⁷

Research by Chambaere et al. suggested that in one-fifth of all the cases studied in Belgium there had been no consent granted for sedation.⁴⁸ While a literature review conducted by Claessens et al. indicated that in 15 of the papers examined it was reported that consent was obtained from a vast majority of the patients who did not have a cognitive impairment.⁴⁹ The most significant factor behind a failure to discuss the matter with a competent patient was a desire to shield them from anxiety and/or the sudden onset of refractory suffering.⁵⁰ In a study of Irish nurses conducted by Dwyer and McCarthy the respondents were clearly aware of the obligation to obtain informed consent and it was noted that this was a concern also demonstrated by a majority of Flemish palliative care nurses in a study by Gielen et al.⁵¹

As the legal status and significance of informed consent appears to be generally recognised among healthcare professionals, the challenge is to most effectively support and further promote the seeking of consent in palliative care. This may require a proactive approach which necessitates early and open discussion with patients. Such an approach was advanced by several participants in the Dwyer and McCarthy study. It was suggested that 'palliative sedation could be discussed much earlier in the patient's disease trajectory and they saw this as a means of promoting the patient's autonomy. The patient's level of awareness of their actual stage in their disease could be ascertained and their wishes for sedation established before things started to change',⁵² This approach may give more control to the patient and serves as a way in which an individual can assert their self-determination at the end-of-life. Although, it is to be remembered that palliative sedation brings about a state of unconsciousness whereby the patient is no longer able to further exercise contemporaneous autonomy. Moreover, there is a lack of evidence on the impact which advance discussions on sedation have on the physical and emotional health of patients.

3.1.4 The refusal of medical treatment

A refusal of medical treatment in palliative care could have significant consequences for the subsequent care of the patient and their prognosis. The patient's

47 A. Beel and others, 'Palliative sedation: nurses' perceptions' (2006) 12 *International Journal of Palliative Nursing* 510; B. Patel and others, 'Nurses' attitudes and experiences surrounding palliative sedation: components for developing policy for nursing professionals' (2012) 15 *Journal of Palliative Medicine* 432.

48 K. Chambaere and others, 'Continuous deep sedation until death in Belgium: a nationwide survey' (2010) 170(5) *Archives of Internal Medicine* 490.

49 P. Claessens and others, 'Palliative sedation: a review of the research literature' (2008) 36(3) *Journal of Pain and Symptom Management* 310.

50 Ibid. 325.

51 Dwyer (note 45); J. Gielen and others, 'Flemish palliative-care nurses' attitudes to palliative sedation: a quantitative study' (2012) 19 *Nursing Ethics* 692.

52 Dwyer (note 45) 5.

refusal of treatment is to be respected however it may be limited based on factors such as their level of capacity. The autonomous decision is also likely to be questioned in circumstances where it conflicts with the sanctity of life or with the advice of healthcare professionals. Chapter 2 of this work highlighted its relevance for the withdrawal of artificial nutrition and hydration (ANH). Despite this, exercising a right to refuse treatment will not always be such a contentious issue and is relevant for many practices at the end-of-life.

In England and Wales, the first application of the right to refuse treatment was the Court of Appeal decision in *Re T (Adult: Refusal of Medical Treatment)*.⁵³ This involved the refusal of a blood transfusion by a person who was raised as a Jehovah's Witness although she was not practising her religion prior to this decision., Lord Donaldson MR commented that:

An adult patient who, like Miss T., suffers from no mental incapacity has an absolute right to choose whether to consent to medical treatment, to refuse it or to choose one rather than another of the treatments being offered. This right of choice is not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent.⁵⁴

Despite reference to an 'absolute right' this quote illustrates how the right of autonomy requires a person to have sufficient mental capacity and suggests that the person's choice is limited to the treatment options proposed by the healthcare professional. Despite these limits, the right of autonomy does provide the patient with a considerable degree of control over medical decisions affecting them. The right to refuse treatment was affirmed in *Airedale NHS Trust v Bland*.⁵⁵ Lord Goff stated that:

[T]he principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes, even though they do not consider it to be in his best interests to do so⁵⁶

In addition to common law protection, the right of autonomy has been recognised and protected by the Irish Constitution and the ECHR.

A person's autonomous decision must be respected even if it is not necessarily in the patient's best interests from a purely medical perspective. In *Re a Ward of Court* Denham J highlighted this point in stating that 'medical treatment may be

53 *Re T (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 649, [1992] EWCA Civ 18.

54 *Ibid.* [1992] EWCA Civ 18 [3].

55 *Airedale N.H.S. v Bland* [1993] AC 789.

56 *Ibid.* 864.

refused for other than medical reasons, or reasons most citizens would regard as rational, but the person of full age and capacity may make the decision for their own reasons.⁵⁷ The right of autonomy as protected by Article 8 of the ECHR was considered in *Pretty v United Kingdom*.⁵⁸ The applicant in *Pretty v United Kingdom* alleged that her rights under Articles 2, 3, 8, 9, and 14 of the ECHR were infringed due to the prohibition on assisted suicide under the Suicide Act 1961 and the refusal of the Director of Public Prosecutions to grant immunity to her husband for assisting in her suicide. The House of Lords did not consider that Article 8 ECHR had any relevance for the ending of life as with Mrs Pretty. This point is demonstrated by the view that although Article 8 ‘offered protection to autonomy during life, it did not say anything about the right of individuals to autonomy over their deaths’,⁵⁹ In the European Court of Human Rights (ECtHR) it was found that Article 8 ECHR allowed for the refusal of medical treatment even if this would result in the death of the patient.⁶⁰ The position of the ECtHR was subsequently affirmed in *Tysi c v Poland*. Notably, in *Tysi c*, the ECtHR recognised positive obligations on the State which emerged from the respect for autonomy.

3.1.5 A demand for medical treatment

The extent to which positive obligations stemming from autonomy are recognised is of relevance for defining the limits of palliative medicine. These obligations have generally been limited in individual cases but raise the question of whether a patient could actively request palliative sedation and, significantly, in what circumstances would that request be granted. While this section will focus on the applicable law in England and Wales for the most part, it should be noted that a right to request continuous deep sedation has been provided for in legislation in France and is discussed in Chapter 6.

The extent to which a person could shape their medical treatment arose in the Court of Appeal decision of *R(Burke) v General Medical Council*.⁶¹ The patient in *Burke* had spino-cerebellar ataxia which would eventually result in him being fully dependent on others for his care. The condition would hamper his ability to communicate but he would retain his cognitive faculties. Consequently, Mr Burke would be aware of pain, discomfort, and could experience fear of choking from oral feeding. Mr Burke became aware of guidance issued by the General Medical Council (GMC) under which ANH would be withdrawn from the patient in certain circumstances. It was the wish of Mr Burke to be fed and for appropriate hydration to be administered until he died of natural causes. As a result, Mr Burke

⁵⁷ *Ward of Court*, [1996] 2 IR 79, 156.

⁵⁸ *Pretty v United Kingdom* (2002) 35 EHRR 1.

⁵⁹ D. Morris, ‘Assisted suicide under the European Convention on Human Rights: a critique’ (2003) *European Human Rights Law Review* 65, 78.

⁶⁰ *Pretty v United Kingdom* (2002) 35 EHRR 1, [63].

⁶¹ *R(Burke) v General Medical Council* [2006] QB 273, [2005] EWCA Civ 1003.

sought judicial review of the GMC guidance to ensure his treatment would be continued beyond the point where he was capable of expressing his wishes.

The case was heard by Munby J and was subsequently appealed by the GMC. Munby J held that the patient had a right to have the treatment continued and that the guidance of the GMC was incompatible with Articles 2, 3, and 8 of the Human Rights Act.⁶² The decision of Munby J went beyond the circumstances of Mr Burke and addressed broader issues of medical law and ethics. In places, propositions of law were advanced by Munby J.⁶³ At one point, Munby J suggested that the competent patient 'decides what is in his best interests and what treatment he should or should not have',⁶⁴ The GMC were concerned that this created an obligation for doctors to provide treatment requested by the patient although it may not be in the patient's best interests.

The Court of Appeal allowed the appeal and held that the GMC guidance was not unlawful. In relation to a potential request for treatment Lord Phillips MR noted:

the right to refuse a proposed treatment gives the patient what appears to be a positive option to choose an alternative. In truth the right to choose is no more than a reflection of the fact that it is the doctor's duty to provide a treatment that he considers to be in the interests of the patient and that the patient is prepared to accept.⁶⁵

However, the Court did indicate that where a competent patient has made clear his or her wish to remain alive through the provision of ANH then the deliberate withdrawal of ANH would not only be a breach of duty but could also lead to a murder charge.⁶⁶ In addition, the Court of Appeal briefly considered a situation which was not of direct relevance to Mr Burke but which had received attention at the time. Evidence was presented in the case that ANH may not only prolong life but could potentially hasten death.⁶⁷ The decision of whether to administer ANH would then be a clinical decision which would be balanced on whether or not ANH would have a palliative effect. On this point it was stated that '[i]t is only in this situation that, assuming the patient remains competent, a patient's expressed wish that ANH be continued might conflict with the doctor's view that this is not clinically indicated.'⁶⁸ The Court of Appeal did not follow Munby J on this issue and instead were of the opinion that 'a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs',⁶⁹ Although the Court believed such a scenario to be extremely unlikely,

62 Article 2 Right to life; Article 3 Prohibition of torture; Article 8 Right to respect for private and family life.

63 *Burke* [2006] QB 273, [22].

64 *Ibid.* [99].

65 *Ibid.* [51].

66 *Ibid.* [53].

67 *Ibid.* [54].

68 *Ibid.* [54].

69 *Ibid.* [55].

circumstances have arisen in which a person requested the administration of sedation at a time far outside the prevailing requisite prognosis.

Kelly Taylor had two genetic conditions resulting in pain which could not be adequately assuaged.⁷⁰ These were Eisenmenger syndrome and Klippel-Feil syndrome. Her condition was incurable and would continue to deteriorate. Mrs Taylor sought to bring about her death and in an attempt to retain a degree of control and dignity she sought to die through the refusal of all forms of nutrition. Mrs Taylor found the experience ‘undignified’⁷¹ and stopped this attempt to end her life after 19 days. Provided she had capacity to refuse treatment there is little reason to believe that her decision would not have been honoured and she would eventually have succumbed to this lack of nutrition.

Mrs Taylor had a prognosis of less than one year and requested sedation which would result in unconsciousness. If granted, the sedation would render her unable to take nutrition or hydration orally and she would require ANH. However, it was set out by advance directive that she would not accept ANH. The cumulative effect is that this would bring about her death in a time far shorter than her prognosis. Mrs Taylor argued that this course of action would be an example of the principle of double effect and that her decision is protected by her right to be free from inhuman and degrading treatment. Despite these arguments there was clear agreement among her doctors, the hospital, and the British Medical Association that to acquiesce to her demands would not be lawful and that the course of treatment sought by Mrs Taylor amounted to euthanasia.⁷²

She brought the claim for sedation before the High Court where she sought to challenge the refusal of her request. Mrs Taylor’s application ended without a decision being issued by the court. A request for an adjournment was denied and Mrs Taylor withdrew her application on the basis that she would pursue other treatments including physiotherapy. Nonetheless, the case demonstrates that a request for sedation is a reality. This is an extreme example but a request could be made in cases where the patient has a much shorter prognosis and represents a greater legal and ethical dilemma. As noted in *Burke* it would be likely that such a decision would ultimately be made according to the patient’s clinical interests rather than solely being dictated by autonomy. Huxtable noted that ‘the right is not limitless; indeed, it quickly becomes apparent that a doctor’s obligation to act in a patient’s best interests underpins (and constrains) the choices that even *competent* patients are empowered to make.’⁷³ Consequently, a future case on this point is likely to depend significantly on the opinion of the healthcare professional.

70 C. Dyer, ‘Dying woman seeks backing to hasten death’ (2007) 334(7589) *British Medical Journal* 329.

71 R. Huxtable, ‘Whatever you want? Beyond the patient in medical law’ (2008) 16(3) *Health Care Analysis* 288, 290; R. Savill, ‘Woman ends “right to die” food protest’ *The Daily Telegraph* (13 August 2005); See also S. McLean, *Assisted Dying: Reflections on the need for Law Reform* (Routledge 2007) 46.

72 McLean (note 71) 46; J. Laurance, ‘Woman goes to court in historic euthanasia case’ *Independent* (13 February 2007).

73 Huxtable (note 71) 292 (emphasis in original).

3.1.6 Capacity in Ireland and England and Wales

The validity of a patient's consent or refusal of treatment is contingent on the patient having sufficient capacity. The assessment of capacity in palliative care can be challenging due to the effects of the illness and the impact of sedative or pain-killing drugs. The Mental Capacity Act 2005 (MCA) governs this area in England and Wales.⁷⁴ While in Ireland, the Assisted Decision-Making (Capacity) Act 2015 (ADM(C)) will frame capacity assessment and support once it is fully commenced.

The starting point in both Ireland and England and Wales is a presumption that the patient has decision-making capacity. This was affirmed in *Re C (Adult: refusal of treatment)*⁷⁵ and was demonstrated in Ireland by *Fitzpatrick and Another v K and Another*.⁷⁶ Laffoy J in *Fitzpatrick* held that 'there is a presumption that an adult patient has the capacity, that is to say, the cognitive ability, to make a decision to refuse medical treatment, but that presumption can be rebutted.'⁷⁷

The functional test for capacity is applied in both jurisdictions. It is an approach that is issue and time specific. The effect is that a person may have sufficient capacity to make certain decisions about their healthcare but there may be more complex decisions which are beyond their level of capacity. Section 2 of the MCA sets out that 'a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'⁷⁸ This establishes a two part test which encompasses an inability to make a decision along with a diagnostic threshold. The disturbance referred to in section 2 could be permanent or temporary.⁷⁹ Examples of impairments or disturbances are listed by the MCA Code of Practice. This supporting document includes 'severe pain' as an example of a temporary factor which can affect a person's ability to make decisions.⁸⁰ The inability to make a decision is determined by whether a person is unable to understand or retain information relevant to the decision, to use and weigh that information, and to communicate his/her decision.⁸¹ Section 1(3) of the MCA set out that '[a] person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.'⁸² On this basis, palliative care patients should be assisted to make their own

74 D. MacManus and Z. Zylicz, 'Implementing Mental Capacity Act in the everyday decisions of the hospice multi-disciplinary team' (2008) 7(3) *Advances in Palliative Medicine* 115.

75 *Re C (Adult: refusal of treatment)* [1994] 1 All ER 819.; Mental Capacity Act 2005, s.1.

76 *Fitzpatrick and Another v K and Another* [2008] IEHC 104.

77 Ibid; Assisted Decision-Making (Capacity) Act 2015, s.8(2).

78 Mental Capacity Act 2005 (MCA), s.2.

79 MCA 2005, s.2(2).

80 Department for Constitutional Affairs, 'Mental Capacity Act 2005: Code of Practice' (The Stationery Office 2007) [4.26].

81 MCA 2005, s.3(1).

82 MCA 2005, s.1(3).

decisions.⁸³ Owing to the condition of the patient this section would require the treatment of reversible causes of confusion so as to promote patient autonomy. Although, Randall highlighted how the decision to be made may actually relate to the underlying cause of confusion thereby leading to a circular application of the law.⁸⁴

The principles informing the determination of capacity in Ireland, pre ADM(C) Act, were outlined in *Fitzpatrick*. Among the principles is the need to consider whether ‘permanent cognitive impairment’ or ‘temporary factors’ have impaired the patient’s cognitive ability to the point where the individual does not understand the nature, purpose, and effect of the treatment or associated consequences at the point when the decision is made. The patient is incapable of making a decision in circumstances where they have ‘not comprehended and retained the treatment information’, ‘not believed the treatment information’, and ‘not weighed the treatment information’.⁸⁵ Section 3 of the ADM(C) Act echoes these points in affirming the functional test for capacity. Section 3(3) of the 2015 Act sets out that ‘[a] person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to him or her in a way that is appropriate to his or her circumstances’.⁸⁶ This is linked to section 8(3) of the 2015 Act which resembles aspects of the MCA 2005 noted above. For instance, section 8(3) requires ‘all practicable steps’ to be taken to help the patient in making a decision. There will of course be cases where such steps are not effective and a treatment decision must be made in circumstances where the patient lacks sufficient capacity.

In England and Wales, decisions where the patient lacks capacity are to be based on the patient’s best interests as set out by section 4 MCA 2005.⁸⁷ The healthcare professional is to take account of ‘all the relevant circumstances’⁸⁸ and must go through a number of steps set out by the MCA. This is not an exhaustive list and it will often be necessary to consider additional factors.⁸⁹ The past and present wishes as well as the patient’s beliefs and values are to be considered.⁹⁰ It may also be necessary to take account of the views of other people including anyone specifically named by the person, or anyone caring for or interested in the

83 National Council for Palliative Care, ‘The Mental Capacity Act in Practice: Guidance for End of Life Care’ (March 2008) ‘ensuring that the person has a hearing aid; providing appropriate technological support and equipment; using simple language or pictures; writing things down; seeking guidance or support from interpreters (signing or language), speech therapists, psychologists or psychiatrists, particularly in complex cases.’

84 F. Randall, ‘The Mental Capacity Act: implications for palliative care’ (EAPC Congress, Vienna 2009).

85 *Fitzpatrick and Another v K and Another* [2008] IEHC 104.

86 Assisted Decision-Making (Capacity) Act 2015 (ADM(C)), s.3(3).

87 See also M. Donnelly, ‘Capacity assessment under the Mental Capacity Act 2005: delivering on the functional approach?’ (2009) 29 *Legal Studies* 464.

88 Mental Capacity Act 2005, s.4(2).

89 Department for Constitutional Affairs (note 80) [5.60].

90 MCA 2005, s.4(6).

welfare of the person in order to determine what would be in the person's best interests.⁹¹ The best interests of the patient should not be confused with what the individual who is consulted would want to occur. Moreover, the MCA does not endow family members or carers with the ultimate right to decide. Such a situation would only occur where such a party has been granted a proxy decision-making power applicable to the decision. Regardless, there is a need to consult these parties in order to inform the best interests assessment, although consultation may not always be possible particularly in emergency cases.

In Ireland, these decisions will be structured by Section 8 of the ADM(C) Act which establishes Guiding Principles. Section 8(6) sets out that any intervention should minimise the restriction of the relevant person's rights and freedom of action.⁹² In addition, due regard should be had for the 'need to respect the right of the relevant person to dignity, bodily integrity, privacy, autonomy' and should also 'be proportionate to the significance and urgency of the matter'.⁹³ The overall effect is that the least restrictive option should be pursued when making a decision for a person lacking capacity. Section 8(7) of the Act requires the intervener to 'permit, encourage and facilitate' the participation of the relevant person as much as possible. Notably, the intervener is to 'give effect, in so far as is practicable, to the past and present will and preferences of the relevant person'.⁹⁴ This would appear to go beyond the consideration of such views required by the MCA.⁹⁵ The 2015 Act also requires the intervener to take account of the beliefs and values of the relevant person as well as any other factors which the person would be likely to consider. In effect, the emphasis on the patient's will and preferences underlines the need to respect a person's autonomy. Section 8(8) of the Act provides for the intervener to consider the views of 'any person engaged in caring for the relevant person', 'any person who has a bona fide interest in the welfare of the relevant person, or', 'healthcare professionals'.⁹⁶ This allows a degree of discretion for the intervener in considering the views and opinions of family members.

A final point to reference is the status of advance decisions or advance care directives. The use of an advance care directive allows the wishes of the patient to be known in circumstances where they no longer have sufficient capacity to make a contemporaneous decision. An advance directive would be relevant for determining best interests under section 4(6)(a) MCA although it would not be decisive.⁹⁷ For an advance decision to be effective it is necessary that it be valid and applicable as specified by section 25 MCA.⁹⁸ Provided both requirements are satisfied then under section 26(1) 'the decision has effect as if he had made it, and

91 MCA 2005, s.4(7).

92 ADM(C) Act 2015, s.8(6).

93 ADM(C) Act 2015, s.8(6).

94 ADM(C) Act 2015, s.8(7).

95 D. Madden, *Medicine, Ethics and the Law* (3rd edn, Bloomsbury Professional 2016) 249.

96 ADM(C) Act 2015, s.8(8).

97 MCA 2005, s.4(6)(a).

98 *HE v A Hospital Trust* [2003] EWHC 1017.

had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued'.⁹⁹ However, there are additional requirements where the advance decision relates to a refusal of life-sustaining treatment. Such a refusal requires a statement that the decision is to apply even when life is at risk, must be in writing, and be appropriately witnessed.¹⁰⁰ As advance decisions for patients receiving palliative care are likely to raise issues around life-sustaining treatment it is necessary that these formalities be complied with.¹⁰¹ As noted above, a patient could possibly request rather than refuse a form of treatment. An advance request could inform an assessment of a patient's wishes and values but is not binding. As such, the MCA does not alter the position that doctors need not offer treatment which is not in accordance with the patient's best interests.

The ADM(C) Act provides a basis in statute for advance decisions in Ireland. As the law currently stands, *Re a Ward of Court, Fitzpatrick v FK*, and *Governor of X Prison*¹⁰² have indicated support for advance decisions in Ireland but provide a precarious basis for the legal status of advance decisions. Part 8 of the ADM(C) Act addresses the status and formalities required for advance decisions. Section 84 of the 2015 Act establishes the requirements for making a valid advance healthcare directive and sets out conditions in which a refusal of treatment would be complied with.¹⁰³ Advance decisions are, for the most part, associated with treatment refusal. Section 84(3) is therefore notable as it provides that '[a] request for a specific treatment set out in an advance healthcare directive is not legally binding but shall be taken into consideration'.¹⁰⁴ Furthermore, in circumstances where the request is not complied with it will be necessary to record the reasons for not complying with the request and to provide this information to the person's designated healthcare representative within a specified period of time.¹⁰⁵ As with the Mental Capacity Act there are requirements for validity and applicability which must be complied with. If a refusal of treatment relates to life-sustaining treatment then it will only apply if it is supported by a statement indicating that it is to apply even where the individual's life is at risk.¹⁰⁶ The proceeding sub-section of the ADM(C) Act specifies that '[a]n advance healthcare directive is not applicable to the administration of basic care to the directive-maker'.¹⁰⁷ Basic care includes 'warmth, shelter, oral nutrition, oral hydration and hygiene measures but does not include artificial nutrition or artificial hydration'.¹⁰⁸ A person can therefore refuse

99 MCA 2005, s.26(1).

100 MCA 2005, s.25(5); See also *An NHS v D* [2012] EWHC 885 (COP).

101 C. Johnston, 'Advance decision-making – rhetoric or reality?' (2014) 34(3) *Legal Studies* 497.

102 *Governor of X Prison v McD* [2015] IEHC 259.

103 ADM(C) Act 2015, s.84(2).

104 ADM(C) Act 2015, s.84(3).

105 ADM(C) Act 2015, s.84(3).

106 ADM(C) Act 2015, s.85(3).

107 ADM(C) Act 2015, s.85(4).

108 ADM(C) Act 2015, s.85(4).

ANH but the provision of basic care will be continued as this care is closely associated with upholding the patient's dignity.

3.2 The concept of dignity in palliative care

The term dignity is regularly used in discussion of end-of-life care. It may be used in the context of palliative care promotion where it evokes ideas of care and the alleviation of suffering or it may be called upon in support of the liberalisation of the law on euthanasia.¹⁰⁹ The ubiquity of the term underlines its status in the discourse on end-of-life care, yet it is a nebulous concept which defies simple definition.¹¹⁰ Feldman wrote that the meaning of the right to dignity is problematic to 'pin down'.¹¹¹ In this vein Binchy commented that '[i]ts meaning depends greatly on the philosophical premises of those who invoke it; the range of such premises is so broad that "dignity" can have completely opposing connotations'.¹¹² This point was also acknowledged by the EAPC which noted that 'dignity seems to be an individual concept including different domains and priorities for each patient'.¹¹³ More direct criticism of the concept includes its description as 'the shibboleth of all perplexed and empty-headed moralists',¹¹⁴ and Waldron's description of dignity as 'soft and mushy'.¹¹⁵ Nevertheless, it has been suggested by Brennan that the malleable nature of dignity may be beneficial as it can respond to and capture the essence of an experience.¹¹⁶

109 H.M. Chochinov and others, 'Dignity and Palliative End-of-Life care' in N Cherny and others (eds) *Oxford Textbook of Palliative Medicine* (5th edn, Oxford University Press 2015).

110 S.W. Smith, *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying Process* (Cambridge University Press 2012) 128 'It can never be more than one of a number of values, principles and policies which pull decision-makers in different directions.'; D. Feldman, 'Human dignity as a legal value: Part 2' (2000) *Public Law* 61, 75 'The content of its central core is not clear, making it an uncertain guide.'; R. Macklin, 'Dignity is a useless concept' (2003) 327 *British Medical Journal* 1419, 1419 'A close inspection of leading examples shows that appeals to dignity are either vague restatements of other, more precise, notions or mere slogans that add nothing to an understanding of the topic.'

111 D. Feldman, 'Human dignity as a legal value: Part 1' (1999) *Public Law* 682, 682.

112 W. Binchy, 'Dignity as a Constitutional Concept' in E. Carolan and O. Doyle (eds), *The Irish Constitution: Governance and Values* (Round Hall 2008) 308; C. O'Mahony, 'There is no such thing as a right to dignity' (2012) 10 *International Journal of Constitutional Law* 551, 551 '... for all the importance and emphasis placed on human dignity in the text of international conventions, domestic constitutions, and court decisions, the elusive nature of the concept has led many commentators to argue that it is, at best, meaningless or unhelpful, and at worst, potentially damaging to the protection of fundamental human rights.'

113 Radbruch (note 11) 283.

114 A. Schopenhauer, *The Basis of Morality* (A. Bullock tr, Dover Publications 2012) 51.

115 J Waldron, *The Harm in Hate Speech* (Harvard University Press 2012) 137.

116 F. Brennan, 'Dignity: A unifying concept for Palliative Care and human rights' (2014) 22(2) *Progress in Palliative Care* 88.

The range of interpretations has not diminished the status afforded to dignity in palliative care.¹¹⁷ In the PALLIUM project, 96.2% of respondents considered human dignity to be a central concept within palliative care.¹¹⁸ In the Dwyer and McCarthy study cited above, several respondents considered palliative sedation to be an intervention which contributed to maintaining dignity in a patient's dying. The WHO definition of palliative care was quoted earlier in this chapter and emphasised a focus on the quality of life and relief of suffering through the treatment of physical, psychosocial, and spiritual issues. It has been suggested that this care 'can readily be conceived of as enhancing dignity'.¹¹⁹ For instance, a systematic review conducted by Pringle et al. illustrated the importance of appropriate symptom control and use of the correct healthcare settings as part of protecting dignity in palliative care.¹²⁰ A review by Johnston et al. identified care actions such as listening, communication, empathy, and involving the patient in decision-making as elements in conserving dignity.¹²¹ Overall, the recognition of dignity in palliative care was summarised by Pringle et al. who stated that:

Across the varied review settings and countries, while differing healthcare systems and approaches may be in operation, there is agreement on core values among palliative care experts: the need for a holistic, individualised approach that promotes patient autonomy and dignity.¹²²

The link between autonomy and dignity has led some to conflate the concepts.¹²³ Others have outlined conceptions of dignity based on ontological perspectives¹²⁴ and virtue.¹²⁵ An interpretation has been advanced by Feldman which is composed of subjective and objective conceptions of dignity. The subjective conception of dignity is 'concerned with one's sense of self-worth, which is usually associated with forms of behaviour which communicate that sense to others.'¹²⁶ Whereas the objective conception of dignity is 'concerned with the state's and other people's attitudes to an individual or group, usually in the light of social norms or

117 Chochinov (note 109) 307.

118 L. Sandman, 'What's the use of human dignity within palliative care?' (2002) 3(2) *Nursing Philosophy* 177; R. Janssens, *Palliative Care: Concepts and Ethics* (Nijmegen University Press 2001).

119 Chochinov (note 109) 307.

120 J. Pringle and others, 'Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: a systematic review' (2015) 29(8) *Palliative Medicine* 675.

121 B Johnston and others, 'Dignity-conserving care in palliative care settings: An integrative review' (2015) 24(13–14) *Journal of Clinical Nursing* 1743.

122 Pringle (note 120) 690.

123 Chochinov (note 109) 306.

124 R.M. Parse, 'Human Dignity: A Humanbecoming Ethical Phenomenon' (2010) 23 (3) *Nursing Science Quarterly* 257.

125 D. Schroeder, 'Dignity: Two Riddles and Four Concepts' (2008) 17(2) *Cambridge Quarterly of Healthcare Ethics* 230.

126 Feldman (note 111) 685.

expectations.¹²⁷ Although an individual may lack capacity and therefore be deprived of dignity in the subjective sense, they would not necessarily be deprived of dignity in the objective sense.¹²⁸ The relevance of this is apparent in the context of palliative and specialist palliative care practices where a patient may be heavily sedated. Such a point was recognised by Feldman in the context of the vegetative state:

patients in a persistent vegetative state can be regarded as having intrinsic human dignity in this objective sense, in that responsible beings owe a moral, and often a legal, duty to have regard to their interests and rights when making decisions affecting their welfare.¹²⁹

It could therefore be suggested that the concept of dignity establishes certain limits. Feldman commented that it is accepted that there are ‘certain things that cannot be done even to unconscious or dependent people without violating their dignity and denying them the respect that is due to them’.¹³⁰ The violation of dignity in healthcare can result in degradation, disempowerment, and a loss of self-worth.¹³¹ In addition, a lack of respect for the dignity of a patient could result in adverse outcomes including ‘denial of access to appropriate treatment, subjection to inappropriate clinical interventions or unwarranted long-term institutionalisation’.¹³² Dignity must therefore have a clear meaning and framework for its application if it is to be useful in practice.¹³³ Accordingly, human rights can serve to provide a framework for the protection of dignity. The principle of dignity may come within the scope of a variety of rights although there are certain rights which have an especially significant role in upholding human dignity.¹³⁴ On this point Feldman included ‘the right to be free of inhuman or degrading treatment, the right to respect for private and family life, the right to freedom of conscience and belief ... and the right to be free of discriminatory treatment’.¹³⁵ The proceeding section will concentrate on the right to be free from inhuman and degrading treatment. A broad approach will be taken which considers its application to dignity as well as its wider relevance for palliative care.

127 Ibid. 686.

128 Donnelly (note 21) 212–213.

129 Feldman (note 111) 686.

130 Ibid. 687.

131 N. Jacobson, ‘A taxonomy of dignity: a grounded theory study’ (2009) 9(3) *BMC International Health and Human Rights*.

132 Writing Group for the Consortium for Health and Human Rights, ‘A Call to Action on the 50th Anniversary of the Universal Declaration of Human Rights. Health and Human Rights’ (1998) 3(2) *Health and Human Rights* cited in S. O’Hanlon and J. Schweppe, ‘Health, dignity and human rights’ (2010) 11(2) *Medico-Legal Journal of Ireland* 97..

133 C. Foster, *Human Dignity in Bioethics and Law* (Hart Publishing 2011) 1.

134 Feldman (note 111) 690.

135 Ibid.

3.2.1 Inadequate palliative care provision as inhuman or degrading treatment?

The right to be protected from torture and inhuman or degrading treatment has been set out in the ECHR,¹³⁶ the Charter of Fundamental Rights,¹³⁷ the International Covenant on Civil and Political Rights,¹³⁸ the United Nations Convention against Torture,¹³⁹ the Universal Declaration of Human Rights, the European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment,¹⁴⁰ and as an unenumerated right in the Irish Constitution.¹⁴¹ Laws on opioid availability, access to medical care at the end-of-life, and inadequate prescribing guidelines can result in the engagement of this right. This section will consider what threshold must be crossed before the right would be engaged and what it requires of States and healthcare professionals.

Under Article 3 ECHR it is set out that '[n]o one shall be subjected to torture or to inhuman or degrading treatment or punishment.'¹⁴² This is an absolute right under the ECHR to which no derogations are permitted. *Ireland v UK*¹⁴³ demonstrated the distinction between torture and inhuman or degrading treatment. The ECtHR took the view that 'this distinction derives principally from a difference in the intensity of the suffering inflicted.'¹⁴⁴ As torture is a much higher threshold, the focus will be placed on inhuman and degrading treatment. Article 3 imposes both positive¹⁴⁵ and negative obligations¹⁴⁶ on States. The negative obligation is absolute in that it sets out that 'no one shall be subject' to the prohibited forms of treatment. In contrast, the positive obligation is not absolute and has largely emerged through ECtHR jurisprudence.¹⁴⁷ This may impose a variety of obligations including:

136 European Convention on Human Rights, Article 3.

137 Charter of Fundamental Rights of the European Union, Article 4 'No one shall be subjected to torture or to inhuman or degrading treatment or punishment.'

138 International Covenant on Civil and Political Rights (1966), Article 7. 'No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.'

139 Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (1984).

140 European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Strasbourg, 26.XI.1987 Text amended according to the provisions of Protocols No. 1 (ETS No. 151) and No. 2 (ETS No. 152), which entered into force on 1 March 2002.

141 *State (C) v Frawley* [1976] 1 IR 365.

142 European Convention on Human Rights, Article 3.

143 *Ireland v United Kingdom* [1978] ECHR 1.

144 *Ibid.* [167].

145 *Z and Others v the United Kingdom* (2002) 34 EHRR 3.

146 *Pretty v United Kingdom* (2002) 35 EHRR 1, [50] 'It may be described in general terms as imposing a primarily negative obligation on States to refrain from inflicting serious harm on persons within their jurisdiction.'

147 J. Herberg and D. Pievsky, 'Article 3: Prohibition of Torture and of Inhuman or Degrading Treatment' in Lord Lester Herne Hill and others (eds), *Human Rights Law and Practice* (2nd edn, LexisNexis 2004) 138.

an obligation on states to pass criminal laws outlawing and punishing ill-treatment amounting to torture or inhuman or degrading treatment; an obligation to investigate arguable breaches of art 3; and an obligation to take reasonable steps to prevent real and immediate risks of torture or inhuman or degrading treatment at the hands of non-state agents.¹⁴⁸

As noted above, there is a high threshold for successfully relying on Article 3 and this has had the effect of limiting its use.

The difference between degrading and inhuman treatment is based on the severity of physical or mental suffering. Inhuman treatment was defined in the *Greek* case as causing 'severe suffering, mental or physical, in the particular situation'.¹⁴⁹ Degrading treatment was also defined in that case as treatment which 'grossly humiliates him before others or drives him to act against his will or conscience'.¹⁵⁰ In *Pretty v the United Kingdom*, degrading treatment was described by the ECtHR as treatment which 'humiliates or debases an individual showing a lack of respect for, or diminishing, his or her dignity or arouses feelings of fear, anguish or inferiority capable of breaking a person's moral and physical resistance'.¹⁵¹ Although the reasoning behind the treatment is a relevant consideration, the absence of a specific intention to humiliate or degrade the person will not exclude the finding of an Article 3 violation.¹⁵² It follows that it is not necessary for the person to 'legally capable to feel degraded or humiliated'.¹⁵³

The experience of bodily injury or physical or mental suffering need not stem from physical violence but may arise due to a naturally occurring illness as in *D v United Kingdom*,¹⁵⁴ *Keenan v United Kingdom*,¹⁵⁵ *Bensaid v United Kingdom*,¹⁵⁶ and *Mouisel v France*.¹⁵⁷ The applicant in *D v United Kingdom* was found to be in possession of a quantity of cocaine upon arriving at Gatwick Airport. He served his prison sentence in England and was to be removed to his home country of St Kitts upon release. While serving his sentence, the applicant was diagnosed as suffering from AIDS. The applicant sought to remain in the UK on compassionate grounds as removal to St Kitts would result in the loss of medical treatment, thereby

148 Ibid.

149 Report of November 5, 1969, Yearbook of the European Convention on Human Rights, Vol. XII (1969) 186.

150 Ibid.

151 *Pretty v United Kingdom* (2002) 35 EHRR 1, [52]; See also *Price v the United Kingdom*, App no 33394/96, (ECtHR, 10 July 2001); *Valašinas v Lithuania*, App no 44558/98, (24 July 2001).

152 *Raninen v Finland*, App no 20972/92 (16 December 1997).

153 Donnelly (note 21) 214.; *Herczegfalvy v Austria* (1992) 15 EHRR 437.

154 *D v United Kingdom* (1997) 24 EHRR 423.; Application of Article 3 to medical treatment first recognised in *X v Denmark* (1992) 15 EHRR 437.

155 *Keenan v United Kingdom* (2001) EHRR 913.

156 *Bensaid v United Kingdom* (2001) ECHR 82; See also S. Palmer, 'AIDs, expulsion and Article 3 of the European Convention on Human Rights' (2005) 5 *European Human Rights Law Review* 533.

157 *Mouisel v France*, App No 67263/01 (14 November 2002), (2004) 38 EHRR 34.

reducing his life expectancy. The Chief Immigration Officer refused this request. The risk to the applicant's health was accepted by the Commission and 'concluded that the removal of the applicant to St Kitts would engage the responsibility of the respondent State under Article 3'.¹⁵⁸ The cumulative effect of these conditions led to the Commission deciding that to remove him from England would result in inhuman treatment by the State in violation of Article 3.

The decision in *D v United Kingdom* demonstrates that the potential of being denied appropriate medical care was sufficient to engage Article 3.¹⁵⁹ This position was summarised in *L v Lithuania*¹⁶⁰ where the ECtHR stated that '... if the source is a naturally occurring illness, the treatment for which could involve the responsibility of the State but is not forthcoming or is patently inadequate, an issue may arise under this provision'.¹⁶¹ This quote demonstrates the relevance of Article 3 to the provision of palliative care as the treatment and care must be available and needs to be adequate for the naturally occurring illness. Nevertheless, it is to be emphasised that the key facts in *D v United Kingdom* are that the patient was already terminally ill and there was no real prospect of appropriate medical care if he were to be extradited. In effect, the case of *D v United Kingdom* did not serve to establish Article 3 as promoting a general right to medical care and treatment for people who would otherwise be expelled from the state.¹⁶² Instead it appears that a complete lack of medical care or inadequate medical care would be required to give rise to a breach of Article 3.

A further way in which a person may be degraded is to impose medical treatment on them, absent their consent. Such treatment was at issue in *Herczegfalvy v Austria*.¹⁶³ At the centre of this case was a compulsorily detained psychiatric patient. The patient was force fed and sedated without his consent, isolated and restraints were used to control his movement. The patient complained that this amounted to a violation of Article 3. The ECtHR identified two necessary elements for successfully invoking the protection offered by Article 3. First, a minimum level of severity must be demonstrated.¹⁶⁴ This threshold will depend on the circumstances of the individual case. For example, in *Kudla v Poland* it was stated that, 'the Court has consistently stressed that the suffering and humiliation involved must in any event go beyond that inevitable element of suffering or humiliation connected with a given form of legitimate treatment or

158 Ibid. [45].

159 See also *Tanko v Finland*, App no 23634/94 (Commission Decision, 19 May 1994) 1 'The Commission does not exclude that a lack of proper care in a case where someone is suffering from a serious illness could in certain circumstances amount to treatment contrary to Article 3 (Art. 3).'

160 *L v Lithuania* (2008) 46 EHRR 22.

161 Ibid. [46].

162 Exceptional circumstances not clarified in cases of *BB v France*, App no 30930/96 (ECtHR, 7 September 1998) or *Tatete v Switzerland*, App no 41874/98 (ECtHR, 6 July 2000).

163 *Herczegfalvy v Austria* (1992) 15 EHRR 437.

164 *Ireland v United Kingdom* [1978] ECHR 1; *Keenan v United Kingdom* (2001) 33 EHRR 913.

punishment.¹⁶⁵ In deciding whether this threshold is met a number of factors must be considered. These include the form of treatment and its physical impact on the individual, the manner in which such treatment is provided, and the use of physical restraint.¹⁶⁶ In *Keenan v United Kingdom* the Court recognised that factors to be considered include ‘the duration of the treatment, its physical and/or mental effects and, in some cases, the sex, age and state of health of the victim.’¹⁶⁷ This illustrates the range of factors which the ECtHR can draw on to identify treatment as being inhuman or degrading.

The second point is that there will be no breach of Article 3 if the treatment is demonstrated to be therapeutically necessary.¹⁶⁸ In *Herczegfalvy*, the ECtHR held that there had been no violation of Article 3 as ‘medical necessity justified the treatment in issue’.¹⁶⁹ On this point, there is a distinction between what is therapeutically necessary and what is in the patient’s best interests. As best interests encompass more than just medical interests it would be possible that treatment is indicated by best interests but not therapeutically necessary.¹⁷⁰ The issue of what is therapeutically necessary is not always clear in specialist palliative care. This was demonstrated in Chapter 2 in relation to the withdrawal of ANH along with the decision to administer palliative sedation. However, it would seem that steps should be taken in advance to demonstrate the therapeutic necessity of treatment.¹⁷¹

The severity threshold may be a more fluid test as indicated by *Selmouni v France*.¹⁷² In *Selmouni*, the ECtHR were of the opinion that ‘the increasingly high standard being required in the protection of human rights and fundamental liberties correspondingly and inevitably requires greater firmness in assessing breaches of the fundamental values of democratic societies’.¹⁷³ What constitutes inhuman or degrading treatment will change over time and a stricter standard may be seen in future. It is to be remembered that the rights set out in the ECHR provide ‘a floor of rights protection rather than a ceiling’.¹⁷⁴ Grosz, Beatson, and Duffy state:

There is no imperative that parties to the Convention should adopt a uniform approach, only that they should not fall below a irreducible minimum, which will be monitored by the Strasbourg institutions. It is therefore open to national courts to develop a domestic jurisprudence under the Convention

165 *Kudla v Poland* (2000) 35 EHRR 198, [92].

166 Donnelly (note 21) 215–216.

167 *Keenan v United Kingdom* (2001) 33 EHRR 913, [109].

168 *Herczegfalvy v Austria* (1992) 15 EHRR 437, [82].

169 Ibid. [83].

170 Donnelly (note 21) 216.

171 *Nevmerzhitsky v Ukraine* (2006) 43 EHRR 32.

172 *Selmouni v France* (2000) 29 EHRR 403.

173 Ibid. [101].

174 Palmer (note 156) 539.

which may be more generous to applicants than that dispensed in Strasbourg, while remaining broadly consistent with it.¹⁷⁵

Accordingly, the courts in Ireland and England and Wales are not prevented from applying a more stringent approach to human rights protection. The ECHR has always been treated as a living instrument and its scope has been greatly expanded by the ECtHR over the years, especially on moral issues. Despite this, there remains a relatively high threshold for successfully relying on Article 3 ECHR which has limited its use.

The connection between palliative care and protection from inhuman or degrading has been highlighted outside of the ECHR. The United Nations Special Rapporteur (SR) on Torture and other Cruel, Inhuman or Degrading Treatment or Punishment, Prof Nowak, stated that ‘the de facto denial of access to pain relief, if it causes severe pain and suffering, constitutes cruel, inhuman or degrading treatment or punishment’,¹⁷⁶ and ‘all measures should be taken to ensure full access and to overcome current regulatory, educational and attitudinal obstacles to ensure full access to palliative care.’¹⁷⁷ In a joint letter from the SR on the Right to Health and SR on Torture to the Chairperson of the Commission on Narcotic Drugs in December 2008 it was stated that ‘[t]he failure to ensure access to controlled medicines for the relief of pain and suffering threatens fundamental rights to health and to protection against cruel inhuman and degrading treatment.’¹⁷⁸ Greater detail was provided in 2013 by the SR on Torture who set out that the denial of pain treatment may result in cruel, inhuman, or degrading treatment if three criteria are fulfilled. This would occur where ‘the suffering is severe and meets the minimum threshold under the prohibition against torture and ill-treatment; when the State is, or should be, aware of the suffering, including when no appropriate treatment was offered; and when the Government failed to take all reasonable steps to protect individuals’ physical and mental integrity.’¹⁷⁹ The SR stated that reasonable steps involve ‘[e]nsuring the availability and accessibility’¹⁸⁰ of WHO Essential Medicines. Although, it was noted that this is also a legal obligation under the Single Convention on Narcotic Drugs, 1961. This begins to

175 S. Grosz and others, *Human Rights: The 1998 Act and the European Convention* (Sweet and Maxwell 2000) 20.

176 Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, ‘Promotion and Protection of all Human Rights, Civil, Political, Economic, Social and Cultural Rights, including the Right to Development’ A/HRC/10/44 (14 January 2009) 23.

177 Ibid.

178 Letter from Manfred Nowak, Special Rapporteur on Torture, and Anand Grover, Special Rapporteur on the right to the highest attainable standard of health, to Her Excellency Ms. Selma Ashipala-Musavyi, Chairperson of the 52nd Session of the Commission on Narcotic Drugs, Ref G/SO 214 (53–21) (10 December 2008) 4.

179 Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, A/HRC/22/53 (1 February 2013) 13.

180 Ibid.

overlap with questions about the right to pain management and will be addressed later in this chapter.

In sum, the right to be protected from torture and inhuman or degrading treatment is of direct relevance to palliative care provision. It establishes a minimum standard for care to be provided while also placing an obligation on the State to investigate potential breaches of the right, as well as establishing an obligation to ensure the availability and accessibility of treatment for pain relief.

3.2.2 The right to physical integrity – respect for private and family life

The right to physical integrity has been recognised in the ECHR, the Oviedo Convention, and the Charter of Fundamental Rights of the European Union. Furthermore, the right to physical integrity is protected through the criminal and tort law on assault. In Ireland, the right to physical integrity was recognised in *Ryan v Attorney General*¹⁸¹ as an unenumerated right under Article 40.3.1° of the Constitution.¹⁸² The right to physical integrity under the ECHR is most closely associated with Article 8 right to respect for private and family life, but has been referenced in discussion of Article 3.¹⁸³ There is an overlap in the interpretation of these Articles but their application is distinguished based on the seriousness of the interference with the rights of the individual. Article 8 applies at a lower threshold but is subject to limits established by Article 8(2).

Respect for private and family life also extends to patients who are judged to lack capacity.¹⁸⁴ In *Glass v United Kingdom* it was argued by the applicants that decisions taken by a hospital authority and its doctors in relation to the treatment of David Glass constituted an interference with the right to respect for personal integrity.¹⁸⁵ David Glass had an operation to alleviate an upper respiratory tract obstruction.¹⁸⁶ There were complications which led to him becoming critically ill. David's condition fluctuated several times leading to discharge and readmission. The doctors discussed the use of morphine with David's mother during one of his readmissions but she was opposed to its administration.¹⁸⁷ Regardless, diamorphine was prescribed for David during a subsequent readmission to the hospital. The family strongly objected to this treatment and so David's care was transferred to his general practitioner. The applicants exhausted all possible legal remedies in the UK and brought the case before the ECtHR. The ECtHR set out that:

181 *Ryan v Attorney General* [1965] IR 294.

182 Bunreacht na hÉireann Article 40.3.1° 'The State guarantees in its laws to respect, and, as far as practicable, by its laws to defend and vindicate the personal rights of the citizen.'

183 *Pretty v United Kingdom* (2002) 35 EHRR 1, [13].

184 Donnelly (note 21) 219.

185 *Glass v United Kingdom* (2004) 39 EHRR 15, [3]; The first applicant is David Glass who is physically and mentally disabled. The second applicant is David Glass' mother.

186 Ibid. [9].

187 Ibid. [12].

the decision to impose treatment on the first applicant in defiance of the second applicant's objections gave rise to an interference with the first applicant's right to respect for his private life, and in particular his right to physical integrity.¹⁸⁸

The breach of Article 8 in this case could have been prevented by the hospital making an application to the court at the time of the dispute. Instead of making a court application, the healthcare professionals sought to impose their best interests assessment.¹⁸⁹ This case signals the importance of a more inclusive approach to decision-making, albeit limited by the type of treatment which could be demanded. In discussing this case, Weller stated that '[a] timely adjudication process must be available to ensure that an [sic] person's right to respect physical and mental integrity as is protected by Article 8 is not compromised by a failure to provide medical treatment, or to deny access to medical treatment on unlawful grounds.'¹⁹⁰

The relevance of an appropriate legal framework subsequently arose in *Tysic v Poland*.¹⁹¹ The applicant in *Tysic* alleged that:

Her right to due respect for her private life and her physical and moral integrity had been violated both substantively, by failing to provide her with a legal therapeutic abortion, and as regards the State's positive obligations, by the absence of a comprehensive legal framework to guarantee her rights.¹⁹²

The legal framework in Poland for abortion lacked a basic decision-making procedure. This served to narrowly constrain cases in which an abortion could be performed.

The applicant in *Tysic* argued that 'the process in her case had not been fair and had not afforded due respect for her private life and her physical and moral integrity.'¹⁹³ The applicant suffered from severe myopia. She became pregnant with her third child but was worried that her retina might detach due to the pregnancy. She was examined by three ophthalmologists who were of the opinion that her pregnancy and the delivery constituted a risk to her eyesight. Despite this, they were not willing to issue a certificate to allow for the pregnancy to be terminated. Further medical advice was sought by the applicant and a general practitioner issued a certificate stating that the pregnancy amounted to a threat to the health of the applicant. Nonetheless, the applicant's request for an abortion was refused by the Head of the Gynaecology and Obstetrics Department in the State

188 Ibid. [70].

189 Ibid. [83].

190 P. Weller, *New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose* (Routledge 2013) 127.

191 *Tysic v Poland* (2007) 45 EHRR 42.

192 Ibid. [67].

193 Ibid. [83].

hospital. The applicant gave birth by Caesarean section and six weeks later her eyesight had further deteriorated.

The ECtHR noted that a decision-making framework for this area should be ‘timely’,¹⁹⁴ ‘fair’,¹⁹⁵ and should not be framed in such a way as to limit its application.¹⁹⁶ These points were made in the context of abortion but it can be argued that these principles are relevant for any area of healthcare which is especially time sensitive such as palliative care.¹⁹⁷ The Court concluded that there was a lack of an appropriate legal framework to assist in identifying whether a lawful abortion could be obtained.¹⁹⁸ Furthermore, the retrospective measures available to the applicant meant that there was no effective mechanism through which the right to respect for her private life could be vindicated in advance. As noted above, the reasoning of the ECtHR in *Tysiāc* serves to establish positive obligations under Article 8 which includes the provision of a timely decision-making framework in a healthcare context.

Similar issues arose in *A, B, and C v Ireland*.¹⁹⁹ There were three applicants in *A, B, and C v Ireland* but it is the discussion of the third applicant which is of most relevance to this work. This woman travelled to England for an abortion as she believed she would not have been able to establish her right to an abortion in Ireland. She had previously received chemotherapy over the course of three years and it was not clear what impact a pregnancy would have on her illness. Although, it was understood that ‘it would be dangerous for the foetus if she were to have chemotherapy during the first trimester.’²⁰⁰ The applicant subsequently became pregnant but was not aware of this when she completed a series of tests for cancer. She researched the health risks and due to the lack of clarity she travelled to England to have an abortion. There were complications stemming from this procedure such as ‘prolonged bleeding and infection’,²⁰¹ These facts led the applicant to complain on the basis of Article 8 and the failure to implement the constitutional right to an abortion where there is a risk to the woman’s life.

The ECtHR recognised the lack of a suitable decision-making framework in Ireland for abortion and highlighted the absence of any procedure for resolving a situation where there are differing opinions between the parties involved.²⁰² The use of medical consultation or litigation options as set out by the Irish Government were viewed as ineffective in such circumstances by the ECtHR.²⁰³ On this basis, the Court concluded that:

194 Ibid. [118].

195 Ibid. [113].

196 Ibid. [116].

197 Weller (note 190) 125 ‘Considered in the light of a right to choose in mental health care, the development of Article 8(2) by the ECtHR in *Tysiāc* establishes a positive entitlement to the timely adjudication of health decisions.’

198 *Tysiāc v Poland* (2007) 45 EHRR 42, [124].

199 *A, B, and C v Ireland* [2010] ECHR 2032.

200 Ibid. [23].

201 Ibid. [26].

202 Ibid. [253].

203 Ibid. [263].

the authorities failed to comply with their positive obligation to secure to the third applicant effective respect for her private life by reason of the absence of any implementing legislative or regulatory regime providing an accessible and effective procedure by which the third applicant could have established whether she qualified for a lawful abortion in Ireland in accordance with Article 40.3.3 of the Constitution.²⁰⁴

The discussion of *A, B, and C v Ireland* moved the focus slightly away from the right to physical integrity and dignity but it demonstrated the importance of complying with the positive obligations raised by Article 8. In particular, the case of *A, B, and C v Ireland* further demonstrated the importance of an appropriate decision-making framework for legally and ethically challenging aspects of healthcare.

In applying the reasoning from the above cases to specialist palliative care it can be argued that there needs to be a decision-making framework in place which ensures that the protection of patients' rights are not illusory. In this regard, the ECtHR in *Tysi c v Poland* made it clear that such a framework needs to be timely, fair, and should not be framed in such a way as to limit its application. Adopting such an approach helps ensure that the patient's rights can be effectively protected and vindicated in practice. Significantly, this section also highlighted how the positive obligations stemming from Article 3 and Article 8 require more than non-interference on the part of the State. As set out earlier, this may raise questions about the steps to be taken in providing appropriate pain relief. This can be framed as a right to pain management but it has also been framed as a right to palliative care.

3.3 A right to palliative care?

A right to palliative care has been advanced by palliative care associations and it has been suggested that there is a basis for a right to palliative care in international law. As noted at the outset of this chapter, human rights have a valuable role in shaping patient care and can serve as a powerful advocacy tool. Recognition of a right to palliative care would therefore be significant in framing international debate and establishing obligations on States for the provision of palliative care. The recognition of a right to palliative care by palliative care associations will be discussed in this section. Second, the basis of the right in international law will be examined. This section will also outline the content and possible weaknesses of such a right.

Chochinov has noted that in end-of-life care there is no 'vocal constituency' as '[t]he dead are no longer here to speak, the dying often cannot speak, and the bereaved are often too overcome by their loss to speak.'²⁰⁵ All of which underlines the potential significance of a right to palliative care.

204 Ibid. [267].

205 H. Chochinov, Address to Standing Committee on Social Affairs, Science and Technology. Quality end-of-life care: The rights of every Canadian. (Senate of Canada 2000).

3.3.1 Advocating for a right to palliative care

A right to palliative care has been proclaimed in statements by international palliative care associations and by political groups. These statements have often been aspirational with little specific detail on how the right can be delivered on at the individual level. There has also been a close connection between the right to palliative care and a right to pain relief and pain management. Moreover, there are other points where the provision of palliative care is closely linked with the right to health. The result of which is to raise questions about the scope of interpretation for a right to palliative care.

In 1992, Margaret Somerville wrote that ‘to leave patients in avoidable pain and suffering should be regarded as a serious breach of fundamental human rights’.²⁰⁶ Somerville further suggested that palliative care should be seen as a human right. In the intervening years there have been multiple declarations on palliative care.²⁰⁷ Among which there have been declarations which have framed palliative care as a human right.

The founding of the African Palliative Care Association led to the Cape Town Declaration of 2002 which asserts that ‘[p]alliative care is a right of every adult and child with a life-limiting disease’.²⁰⁸ The Declaration encourages the provision of appropriate drugs, the establishment of programmes of education, and the provision of palliative care across all levels of care.²⁰⁹ A 2003 European Committee of Ministers recommendation on the organisation of palliative care described palliative care as ‘an integral part of the health care

206 M. Somerville, ‘Human Rights and Medicine: The Relief of Suffering’ in I. Cotler and F.P. Eliadis (eds) *International Human Rights Law: Theory and Practice* (Canadian Human Rights Foundation 1992); M. Somerville, *Death Talk* (2nd edn, McGill-Queen’s University Press 2014) 227.

207 World Medical Association, ‘Declaration of Venice on terminal illness’ (1983) 287 (6405) *British Medical Journal (Clinical Research Ed.)* 1646; J Stjernswärd and others, ‘Opioid availability in Latin America: The Declaration of Florianopolis’ (1995) 10(3) *Journal of Pain and Symptom Management* 233; Barcelona Declaration on Palliative Care (1995) 3(1) *European Journal of Palliative Care* 15; The Poznan Declaration (1998) 6(2) *European Journal of Palliative Care* 61; L. Radbruch and others, ‘The Budapest Commitments: setting the goals. A joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Help the Hospice’ (2007) 21 *Palliative Medicine* 269; Panama Proclamation – Proclamation of Pain Treatment and the Application of Palliative Care as Human Rights (2008); Wuhan Declaration (2009); Lucknow Declaration/Palliative Care Declaration (2011); L. Radbruch and others, ‘The Lisbon Challenge: acknowledging palliative care as a human right’ (2013) 16(3) *Journal of Palliative Medicine* 301; World Medical Association, ‘WMA Declaration on End-of-Life Medical Care’ (Uruguay 2011); European Declaration on Palliative Care (2014); Montreal Declaration on Hospice and Palliative Care (2014).

208 L. Mpanga Sebuyira and others, ‘The Cape Town Palliative Care Declaration: home-grown solutions for Sub-Saharan Africa’ (2003) 6(3) *Journal of Palliative Medicine* 341, 342.

209 Ibid. 342–343.

system and an inalienable element of a citizen's right to health care'.²¹⁰ In 2004, an international working group convened by the European School of Oncology stated that '[t]here should ... be free access to palliative care ... for all cancer patients, as a fundamental human right'.²¹¹ A further argument for the recognition of palliative care as part of the international right to health emerged in 2005 with the Montréal Statement on the Human Right to Essential Medicines.²¹²

In 2005, the Korea Declaration was agreed at the 2nd Global Summit of National Hospice and Palliative Care Associations. In line with this Declaration governments must '[m]ake access to hospice and palliative care a human right'.²¹³ It also addressed education, the expansion of palliative services, and called on governments to identify and remove legal barriers to the adequate use of opioid analgesics including morphine. The International Association of Hospice and Palliative Care along with the Worldwide Palliative Care Alliance issued a Joint Declaration and Statement of Commitment on Pain Relief as Human Rights in 2008. In this declaration it was agreed that the various associations and organisations would '[i]dentify, develop and implement strategies for the recognition of palliative care and pain treatment as fundamental human rights'.²¹⁴ The Joint Declaration also recognised the role of the law in facilitating the provision of palliative care. For instance, it calls on palliative care representatives among others to collaborate with governments and policy makers to 'adopt the necessary changes in legislation to ensure appropriate care of patients with life limiting conditions' and 'to identify and eliminate regulatory and legal barriers which interfere with the rational use of controlled medications'.²¹⁵

A significant step in advocating for a right to palliative care was the Prague Charter as agreed by the European Association for Palliative Care, International Association for Hospice and Palliative Care, Worldwide Palliative Care Alliance, Human Rights Watch, and the Union for International Cancer Control. The Prague Charter clearly identifies palliative care as a legal obligation and suggests that the failure to ensure appropriate access could violate the right to health as well as constituting cruel, inhuman, or degrading treatment. The Charter calls on governments 'to ensure that patients and their families can realize the right to access palliative care by integrating such care into healthcare policies, as well as

210 Council of Europe, 'Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care' (CM(2003)130) 7.

211 S.H. Ahmedzai and others, 'A new international framework for palliative care' (2004) 40(15) *European Journal of Cancer* 2192, 2192.

212 T. Pogge, 'Montréal Statement on the human right to essential medicines' (2007) 16 (1) *Cambridge Quarterly of Healthcare Ethics* 97.

213 Korea Declaration on Hospice and Palliative Care (March 2005) 1.

214 International Association for Hospice and Palliative Care, and Worldwide Palliative Care Alliance, 'Joint Declaration and Statement of Commitment on palliative care and pain treatment as human rights' (2008) 22(4) *Journal of Pain and Palliative Care Pharmacotherapy* 300, 301.

215 Ibid.

ensuring access to essential medicines'.²¹⁶ It also calls on the Council of Europe, the European Union, the WHO, World Health Assembly, World Medical Association, and the International Council of Nurses to promote the right to palliative care.

The Mumbai Declaration of 2014 highlighted the right of children to a high-quality of palliative care.²¹⁷ Also in 2014, at the World Health Assembly in Geneva it was stated that 'access to palliative care and to essential medicines ... contributes to the realization of the right to the enjoyment of the highest attainable standard of health and well-being'.²¹⁸ In sum, these declarations underline the contribution of a human rights discourse to palliative care advocacy. However, the legal basis of a right to palliative care is not consistently defined. In several declarations calls for a right to palliative care appear to stand alone, while at other points it would seem that the right is based on the international right to health.

3.3.2 *The basis of a right to palliative care in international law*

It has been suggested by Brennan,²¹⁹ Gwyther et al.,²²⁰ and Negri²²¹ among others that the right to health can be interpreted in a manner which implies a right to palliative care.²²² In particular, Article 12 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) provides that '[t]he States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health'.²²³ Both the UK and Ireland are signatories of the ICESCR and are therefore bound to protect the right to health. This right is one of 'progressive realisation'.²²⁴ Steps taken to protect and promote the right must be commensurate with the resources of the State. This is in contrast to the ECHR rights discussed earlier in this chapter which are immediately realisable. However, under the ICESCR there is no appeal

216 The Prague Charter: Urging governments to relieve suffering and recognize palliative care as a human right, <<https://hospicecare.com/uploads/2013/6/PragueCharterPetition.pdf>> accessed 30 October 2017.

217 International Children's Palliative Care Network, 'Mumbai Declaration' (2014).

218 World Health Organization, 'Strengthening of palliative care as a component of integrated treatment within the continuum of care' (EB134.R7) 2.

219 F. Brennan, 'Palliative care as an international human right' (2007) 33(5) *Journal of Pain and Symptom Management* 494.

220 L. Gwyther and others, 'Advancing palliative care as a human right' (2009) 38(5) *Journal of Pain and Symptom Management* 767.

221 S. Negri, 'Universal Human Rights and End-of-Life Care' in S. Negri and others (eds), *Advance Care Decision Making in Germany and Italy: A Comparative, European and International Law Perspective* (Springer 2013).

222 World Health Organization, 'Constitution of the World Health Organization' (1946) 'The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.'; Universal Declaration of Human Rights, Article 25; European Charter of Patients' Rights, Article 11.

223 International Covenant on Economic, Social, and Cultural Rights, Article 12.

224 International Covenant on Economic, Social, and Cultural Rights, Article 2(1).

process or complaint mechanism, although states must report to the Committee which oversees the Covenant.

Guidance on the interpretation of the right to health is contained in general comment no. 14 of the Committee on Economic, Social and Cultural Rights. Paragraph 25 of which sets out the need for ‘attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity.’²²⁵ The general comment sets out an obligation on States ‘to respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons, ... to preventive, curative and palliative health services’.²²⁶ Moreover, the Committee recognises several core obligations with which States cannot justify non-compliance as they are non-derogable. These core obligations are linked to general comment no. 3 and ensure a minimum level of protection in areas such as primary health care. Of specific relevance are the following core obligations:

- a To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
- b To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs;
- c To ensure equitable distribution of all health facilities, goods and services;
- d To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population ...²²⁷

In the context of palliative care these obligations would require States to provide universal access to palliative care services, the provision of essential listed medicines for symptom control and pain relief, and the adoption and implementation of a national palliative care strategy and policy based on epidemiological evidence.

The operationalisation of the right to health can be facilitated through use of the AAAQ framework, namely availability, accessibility, acceptability, and quality.²²⁸ This framework assists in establishing the normative dimensions of a right to health and draws out appropriate standards and benchmarks for practice. Gwyther outlines the meaning of the AAAQ framework for palliative care. She suggests that palliative care should be available in adequate ‘quantities within a country’s public health facilities and other health care facilities ... It should be integrated into mainstream health care so that psychosocial support and symptom control are

225 Office of the High Commissioner for Human Rights, ‘CESCR General Comment No. 14: The Right to the Highest Attainable Standard of Health’ [25].

226 Ibid. [34].

227 Ibid. [43].

228 S. Gruskin and others, ‘Rights-based approaches to health policies and programs: articulations, ambiguities, and assessment’ (2010) 31(2) *Journal of Public Health Policy* 129.

available from the time of diagnosis.²²⁹ Gwyther further suggests that essential palliative medicines should be available. Four elements are identified for accessibility, these are non-discrimination, physical accessibility, economic accessibility, and information accessibility. In effect, palliative care should be widely accessible regardless of age, economic means, physical capacity, or geographical location. In relation to acceptability Gwyther sets out that '[p]alliative services should be respectful of culture, gender and age; respecting confidentiality and aiming to improve quality of life of patients and family members.'²³⁰ The final element to address is quality. On this point, it is stated that '[h]ealth facilities, goods and services must also be scientifically and medically appropriate and of good quality. They should follow minimum standards that are appropriate to the individual country's resources.'²³¹

As previously referred to, States have an obligation to make essential drugs available. The World Health Organization set out that '[e]ssential medicines are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality and adequate information, and at a price the individual and the community can afford.'²³² Negri suggests that if States are to achieve this goal it requires the implementation of 'an effective system of supply and distribution' and requires the creation of a 'regulatory framework that allows public health systems, both in the public and private sectors, to obtain, prescribe, and dispense these drugs.'²³³ The current WHO Model List of Essential Medicines includes 22 medicines for pain and palliative care. This includes non-opioids, opioid analgesics, and medicines for other common symptoms in palliative care.²³⁴ The availability of such drugs is not dependent solely on inclusion in the list of essential medicines but is influenced by the system of international narcotics control such as the Single Convention on Narcotic Drugs 1961.

In the preamble to the 1961 Convention it was stated that 'the medical use of narcotic drugs continues to be indispensable for the relief of pain and suffering and that adequate provision must be made to ensure the availability of narcotic drugs for such purposes'.²³⁵ Despite recognition of the pain relief function, many countries have enacted legislation resulting in strict control of opioids which has

229 L. Gwyther, 'Palliative care as a human right' (2014) *Cancer Control* 116, 119 <<http://www.cancercontrol.info/wp-content/uploads/2014/08/116-121-Gwyther.pdf>> accessed 30 October 2017.

230 Ibid.

231 Ibid.

232 World Health Organization, 'Essential Medicines' <http://www.who.int/topics/essential_medicines/en/> accessed 30 October 2017.

233 Negri (note 221) 27.

234 World Health Organization, 'WHO Model List of Essential Medicines' (20th list, March 2017).

235 Single Convention on Narcotic Drugs 1961, preamble; See also United Nations, Convention on Psychotropic Substances 1971, preamble 'Recognizing that the use of psychotropic substances for medical and scientific purposes is indispensable and that their availability for such purposes should not be unduly restricted ...'.

deprived palliative care patients of access to appropriate drugs.²³⁶ Jurisdictions have often focused on the prevention of illicit drug trafficking and this has constrained the availability of narcotic drugs for medical and scientific purposes. In the joint letter from the SR on the Right to Health and SR on Torture to the Chairperson of the Commission on Narcotic Drugs, cited above, it was stated that '[l]ack of access to essential medicines, including for pain relief, is a global human rights issue and must be addressed forcefully'.²³⁷ This again emphasises the close connection between the protection of human rights and the provision of palliative care. Despite this, the instruments cited do not contain an explicit right to palliative care. Instead, Brennan advances an argument based on the broad WHO definition of 'health' and 'palliative care'. For instance, '[t]he provision of healthcare occurs in a continuum, which includes serious illness, dying and death'.²³⁸ This leads Brennan to suggest that the international right to health effectively implies a right to palliative care.

3.3.4 The basis of a right to palliative care in domestic law

Although Ireland and the United Kingdom are signatories of the ICESCR, the right to health is not expressly provided for in the domestic law of either jurisdiction. The right to health is challenging for both politicians and the judiciary. It is a right which raises questions about resource allocation and results in a tension in the separation of powers doctrine. For instance, were a court to recognise a positive right to health this could place an obligation on the State to provide appropriate infrastructure and/or medical treatment in realisation of such a right. This could have significant financial implications and impact on national health policy objectives.

There have been a number of cases in Ireland which have challenged the failure to provide appropriate healthcare services. The plaintiffs in these cases have relied upon constitutional rights. The Constitution of Ireland contains both numerated and unenumerated rights. Consequently, there is potential scope for the interpretation of the Constitution in a manner which provides for a right to health. At one point there appeared to be judicial recognition of the right to health but that was rejected in a subsequent decision.

In *Heeney v Dublin Corporation* tenants in social housing claimed that there was an obligation on the local authority under the terms of their tenancy agreement to ensure an efficient elevator service was provided. In this instance, it was

236 Human Rights Watch, 'Global State of Pain Treatment: Access to Medicines and Palliative Care' (Human Rights Watch 2011) 22. 'Key informants from 34 of 40 countries said that doctors were hesitant to prescribe opioids because of fear of legal sanction for mishandling them, such as criminal sanctions or professional sanctions such as license revocation.'

237 Nowak (note 178) 4.

238 F. Brennan 'Paediatric Palliative Care as a Basic Human Right' in R. Pfund and S. Fowler-Kerry (eds) *Perspectives on Palliative Care for Children and Young People: A Global Discourse* (CRC Press 2010) 14.

stated by the court that 'there is a hierarchy of constitutional rights and at the top of the list is the right to life, followed by the right to health.'²³⁹ In *In the Matter of Art 26 of the Constitution and the Health (Amendment) (No 2) Bill 2004* counsel advanced an argument that there was a right to healthcare based on the right to life, the right to bodily integrity, and the right to human dignity of the person.²⁴⁰ The Supreme Court rejected the existence of a right to health in circumstances where it would result in an obligation on the state to provide free healthcare.²⁴¹ While the ICESCR does not establish a right to free healthcare the decision of the Court illustrates a reluctance in recognising economic, social, and cultural rights.²⁴² On the basis of the case law in Ireland to date, Madden suggested that 'it is unlikely that an action taken against the State on constitutional grounds for failing to provide necessary healthcare services would succeed.'²⁴³ A significant concern in such a case would be the separation of powers and a decision could result in an interference with the function and powers of the executive.

These concerns are also prevalent in England and Wales as evidenced by *R v Secretary of State for Social Services ex parte Hincks*.²⁴⁴ The Secretary of State had approved plans for additional services to be provided at a local orthopaedic hospital. Owing to the cost of these plans it was decided that it could not proceed due to a lack of funds. Several patients had been on a waiting list for a considerable time and sought a declaration from the court that the Secretary of State and the health authorities were in breach of the duty to provide a comprehensive health service. At first instance, Wien J set out that it was not the function of the court to direct Parliament on the allocation of financial resources. On appeal, Lord Denning observed that while the Secretary of State had a duty under the NHS Act 1977, his duty was to provide services 'to such an extent as he considers necessary to meet all reasonable requirements such as can be provided within the resources available'.²⁴⁵ In effect, it is permissible to take account of financial considerations in determining whether treatment is to be provided to a specific patient or group of patients.

In sum, these cases suggest that it is unlikely that a right to palliative care would be recognised and enforced in either jurisdiction. It would be an example of significant judicial activism and would directly strike at the separation of powers. In addition to the international right to health, Brennan has suggested that a right to palliative care may be based on a number of alternative human rights foundations.²⁴⁶ These include a basis in dignity, freedom from inhuman or degrading

239 *Heeney v Dublin Corporation* [1998] IESC 23, [16].

240 *In the Matter of Art 26 of the Constitution and the Health (Amendment) (No 2) Bill 2004* [2005] IESC 7.

241 Madden (note 95) 32.

242 Irish Human Rights Commission, 'Making Economic, Social and Cultural Rights Effective' (Dublin 2005).

243 Madden (note 95) 34.

244 *R v Secretary of State for Social Services ex parte Hincks* (1979) 123 Sol Jo 436; See also *R v Central Birmingham Health Authority, ex parte Walker* (1987) 3 BMLR 32.

245 *Hincks* [1980] 1 BMLR 93, 95.

246 F. Brennan and L. Gwyther, 'Human Rights Issues' in Cherny (note 109) 274.

treatment, and the right to non-discrimination and equality. Regardless of the basis, a right to palliative care would still face the same challenges of recognition and enforcement in Ireland as well as in England and Wales. In the alternative, rights of equality and freedom from inhuman or degrading treatment are not solely rights of progressive realisation as in the ICESCR but are instead protected under the ECHR in addition to recognition in the domestic legal framework. These are rights which can be drawn on by a person in their individual circumstances, as outlined in previous sections, and may prove a more effective tool in improving the provision of palliative care. Nonetheless, it is recognised that people in receipt of palliative care may not always be in a position to legally challenge failings in the provision of their care. The international right to health and its role in advancing a right to palliative care may still prove beneficial at the international level.

The standard of palliative care provision in Ireland and the United Kingdom is generally good but there are many countries where provision is inadequate.²⁴⁷ This point was touched on early in Chapter 1. Research by the International Observatory on End of Life Care found that among 234 countries, 42% lacked a delivery system for palliative care.²⁴⁸ A study by Human Rights Watch indicated extremely poor access to palliative medicines in Sub-Saharan Africa.²⁴⁹ This study also demonstrated low use of strong opioids in Armenia, Azerbaijan, Belarus, Kazakhstan, Romania, Russia, Tajikistan, Turkmenistan, Uzbekistan, and the Ukraine.²⁵⁰ Research into inadequate use of opioid medicines in 12 European countries was completed under the Access to Opioid Medication in Europe (ATOME) project.²⁵¹ This project identified barriers to opioid provision including legislative barriers, national policies, societal attitudes, knowledge, and economic barriers which limited sufficient access. A right to palliative care can further highlight these deficits and weaknesses in palliative care. It can serve as a valuable tool in advocacy and influencing development at the national level. However, it will not act as a global panacea for the development of palliative care.²⁵² It is but one part of a broader framework which must be put in place to ensure the promotion and delivery of effective palliative care for patients and their families.

3.4 Conclusion

This chapter set out to characterise and delineate the role of human rights in shaping palliative care provision. In particular, the chapter engaged with the right of autonomy, the concept of dignity, protection from inhuman or degrading

247 Economist Intelligence Unit, 'Quality of Death Index' (2nd edn, The Economist 2015).; Human Rights Watch (note 244).

248 T. Lynch and others, 'Mapping levels of palliative care development: a global update' (2013) 45 *Journal of Pain and Symptom Management* 1094.

249 Human Rights Watch (note 236) 29.

250 Ibid. 57–58.

251 L. Radbruch and others, 'Access to Opioid Medication in Europe: Final report and Recommendations to the Ministries of Health' (November 2014).

252 Brennan (note 219) 497–498.

treatment, physical integrity, and the right to palliative care. Each of these rights shapes the provision of palliative care either through positive and/or negative obligations. Yet, as was noted at the outset there were many more rights which could have been examined including the right to die a natural death, and the right of equality. Human rights serve as a benchmark for care as well as defining the limits of clinical practice. They must be incorporated and protected by professional guidelines and other elements that comprise the legal framework. The following chapters will reflect on how the wider legal framework can contribute to human rights protection. In the context of palliative and specialist palliative care this requires consideration of the law's influence on patient involvement in treatment decisions, the availability of all levels of palliative care, and drug control laws, regulations, and practices. In addition, the legal framework must also address the fear of legal sanctions so healthcare professionals and patients have greater certainty about the care to be provided. To achieve this, specialist palliative care practices must be clearly demarcated and have a well-defined legal basis.

4 The legal framework for palliative care in the United Kingdom and Ireland

4.0 Introduction

The United Kingdom and Ireland have traditionally been to the forefront of palliative care development. Both jurisdictions have also ranked highly in international measures for the quality of palliative care.¹ This is not to suggest that palliative care in either jurisdiction is free from faults or is not faced with legal, ethical, and clinical challenges. In particular, the legal framework which shapes its provision is not easily delineated. Part of this framework was highlighted in previous chapters which demonstrated the role and impact of human rights and principles which serve to promote patient care. These include the right to bodily integrity, protection from inhuman or degrading treatment, right of autonomy, and the concept of dignity. These must be given effect throughout the legal framework for palliative care. Chapter 2 of this work drew attention to the role of the criminal law and intention in defining the legitimacy of specialist palliative care practices. In addition to criminal law and human rights, the legal framework is shaped by professional standards and guidelines. There is no legislation in either the UK or Ireland which deals expressly with palliative or specialist palliative care practices. Although, there have been several unsuccessful attempts to legislate for the area.

The fragmented nature of the legal framework places an added burden on healthcare professionals who must be aware of the legal boundaries of medical practice. Inadequacies in the legal framework or knowledge of the framework have the potential to impinge on the care provided to patients at the end of life. Consequently, this chapter outlines the remaining elements of the legal framework in the UK and Ireland. In addition, the EAPC framework on palliative sedation will be examined. It is argued that greater coherence is required in the framework in the UK and Ireland in order to promote consistency and clarity for both the healthcare professional and the patient. Healthcare professionals should have a clear understanding of the limits of the care which can be provided, as well as being supported by a comprehensive decision-making framework to assist in deciding what level of palliative care may be required and what steps should be

1 Economist Intelligence Unit, 'Quality of Death Index' (2nd edn, The Economist 2015).

taken when commencing certain practices. As was noted in Chapter 2, the legal framework for palliative and specialist palliative care must deliver on several points. It must provide a clear legal distinction between euthanasia and specialist palliative care practices, it must protect the human rights of the patient, and it must respond to broader debates about end-of-life care. This chapter will also highlight the potential of the legal framework to ensure greater national consistency in palliative care resource provision.

4.1 The legal framework in England and Wales for palliative care

Palliative care in the United Kingdom has grown from the work of charities and champions of the practice such as Dame Cicely Saunders. Government involvement came relatively late, at a time when much had already been done to bring palliative medicine to specialty status. Increased government involvement has brought with it a focus on policy and plans for the development of palliative care. Plans have been developed for England, Wales,² Scotland,³ and Northern Ireland.⁴ Several of the plans for England and Wales will be outlined as they provide an image of palliative care development and the priorities for action. The majority of discussion in this section will be grounded in the English healthcare system. This section will then turn to consider the role and framework provided by the General Medical Council, the National Institute for Health and Care Excellence, Clinical Commissioning Groups, the Liverpool Care Pathway, and attempts to legislate for palliative care. These establish a diverse range of guidance and it is important to reflect on their contribution to palliative care practice.

4.1.1 Shaping palliative care provision and development

Although the development of palliative care was drawn out in Chapter 1 this neglected to trace the influence of strategic planning documents. Palliative care strategies and plans have developed over time in response to the particular needs of each country. Undoubtedly, these documents address important aspects of care but a recurring feature is that the legal framework is regularly at the periphery, if even addressed. In effect, the legal framework is an often overlooked factor in the provision and development of palliative and specialist palliative care.

2 NHS Wales, 'Palliative and End of Life Care Delivery Plan' (March 2017); NHS Wales, 'Together for Health, Delivering End of Life Care' (NHS Wales Health Board 2013).

3 NHS Scotland, 'Living and Dying Well: A National Action Plan for End of Life Care in Scotland' (The Scottish Government 2008); The Scottish Government, 'Strategic Framework for Action on Palliative and End of Life Care 2016–2021' (The Scottish Government 2015).

4 Department of Health, Social Services and Public Safety, 'Living Matters, Dying Matters' (Department of Health, Social Services and Public Safety 2010).

A foundational document in England and Wales for end-of-life care is the 1995 'Policy Framework for Commissioning Cancer Services'.⁵ It is best known as the Calman–Hine Report and was the first comprehensive report on cancer care services in England and Wales. The Calman–Hine Report was motivated by a need to address inadequacies in cancer care including what was described as the 'cancer lottery'.⁶ The focus of the report was primarily on cancer services but specific recommendations were made for the provision of palliative care.

The Calman–Hine Report was cognisant of the ad hoc development of hospice care owing to the efforts of the voluntary sector which led to poor links with health authorities and purchasers in certain locations. This left open the possibility of inconsistent care across healthcare providers. As a result, it was recommended that quality standards and operational policies developed by the National Council for Hospice and Specialist Palliative Care Services as well as leading palliative care units be widely adopted to encourage high standards of care.⁷ Inconsistent development in palliative care remained a persistent issue in the time after the report's publication. By the year 2000, only a third of NHS health authorities had produced palliative care strategies and provision of care remained uneven.⁸

The next significant development was the NHS Cancer Plan of 2000. The plan provided for an increase in the funding of palliative services to a point which would match the contribution of the voluntary sector. Such investment was needed due to the emergence of a 'postcode lottery' whereby many patients were not able to die in their preferred location due to the absence of community specialist palliative care teams in parts of the country combined with inadequate access to out-of-hours nursing care. The NHS Cancer Plan sought to expand the provision of palliative care and to implement aspects of the Calman–Hine Report. It included what were aspirational statements, for instance, '[a]ll patients should have access to the specialist palliative care advice and services that they need.'⁹ Overall, the plan identified the need for greater public funding of hospice and specialist palliative care services while also underlining the need to increase the provision of palliative services across England.

In 2008, the Department of Health published 'End of Life Care Strategy: Promoting high quality care for all adults at the end of life'.¹⁰ This document has informed many of the subsequent strategies and plans proposed for palliative and

5 The Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales, 'A Policy Framework for Commissioning Cancer Services' (Department of Health 1995).

6 R.A. Howard, 'The Calman–Hine report: a personal retrospective on the UK's first comprehensive policy on cancer services' (2006) 7(4) *The Lancet Oncology* 336. cancer lottery – 'the term described a state of affairs in which the chances of positive or negative outcomes for an individual patient were determined by their access to cancer specialists.'

7 Expert Advisory Group (note 5) 16.

8 NHS, 'The NHS Cancer Plan' (Department of Health 2000) 67.

9 Ibid.

10 Department of Health, 'End of Life Care Strategy: Promoting high quality care for all adults at the end of life' (Department of Health 2008).

end-of-life care. The aim of the strategy was to facilitate a significant improvement in access to high quality care for individuals nearing the end of life.¹¹ It was envisaged that high quality care should be available regardless of location and it should not be influenced by individual characteristics. The strategy identified ten objectives which would contribute to achieving the overall aim. Objectives included ensuring people are treated with dignity; providing appropriate pain and symptom management to promote quality of life; access to physical, psychological, social, and spiritual care; the promotion of harmonious and consistent care in all care settings; ensuring adequate education and training of health and social care professionals in end of life care; and ensuring that the needs, priorities, and preference of each individual in the context of end of life care are 'identified, documented, reviewed, respected and acted upon wherever possible'.¹² These objectives raise issues concerning human rights and the decision-making framework in palliative care yet the legal framework appears to be peripheral to the strategy. The legal framework is directly referenced in two paragraphs in chapter one. This limited reference noted that the strategy was developed in the context of the existing legal framework. It follows that the strategy described the Mental Capacity Act 2005 as being '[a]n important element' of the framework but no further detail was provided.¹³ Reference is also made to the debate about the legal status of euthanasia and assisted dying but the strategy suggests that this is an issue outside of its purview.¹⁴ In effect, the potential normative influence of the legal framework is overlooked.

The strategy is especially detailed and addresses issues of funding, infrastructure, and professional competencies. There is a focus on raising the profile of end-of-life care and promoting greater coordination of care. The strategy also calls for a cultural change to encourage greater discussion of end-of-life care. This is one of the few occasions where the role of the legal framework is alluded to. For instance, '[a] change in culture will not happen overnight. ... It will also require the involvement and support of regulators, of the NHS, social care and of the professions. The Mental Capacity Act ... may also encourage greater willingness to initiate discussions.'¹⁵ The reluctance of the Department of Health to engage in more in-depth discussion of the legal framework is somewhat understandable. The strategy concentrates on suggestions which are realisable and can, for the most part, be overseen by the Department. In contrast, the legal framework is more fragmented which leads to issues of diffuse responsibility, reporting, and oversight for palliative care.

Due in part to the manner in which healthcare is commissioned, there began to be a greater focus on bringing about change from the local level. 'Ambitions for Palliative and End of Life Care' was developed by the NHS along with the

11 Ibid. 33.

12 Ibid.

13 Ibid. 30

14 Ibid. 29–30.

15 Ibid. 50.

National Palliative and End of Life Care Partnership.¹⁶ The partnership is composed of bodies such as NHS England, Marie Curie, Sue Ryder, General Medical Council, Association of Palliative Care Social Workers, Care Quality Commission, and the Association for Palliative Medicine. The framework published by this group set out key aims and ambitions intended to improve the quality of care at the end of life through a focus on local action. The ambitions called for each person to be seen as an individual and to receive fair access to care, maximising comfort and wellbeing, coordinated care, staff prepared to care, and each community is prepared to help. In order to realise these ambitions, eight foundations must be in place. The foundations are personalised care planning, shared records, evidence and information, education and training, 24/7 access to care, co-design, leadership, and involving, supporting, and caring for those important to the dying person. Although the Ambitions framework encourages a bottom-up approach to palliative care development, the aims and foundations have been expressed in previous plans and strategies. In some respects this suggests that challenges in the provision of palliative care have not been fully addressed despite the proliferation of planning documents.

The 2015 report titled 'Dying Without Dignity' published by the Parliamentary and Health Service Ombudsman served to define and articulate key themes in poor palliative care provision.¹⁷ Key themes included poor symptom control, poor communication, inadequate out-of-hours services, poor care planning, delays in diagnosis and referrals for treatment, and failures to recognise that people are dying. Failings in these areas were illustrated through the use of twelve case studies which highlighted how each of these themes represented an identified failure in the care of a person at an extremely vulnerable point in their life. The examples come from different healthcare settings and from all parts of the country. The report serves to emphasise the need for the NHS to improve the standard of symptom control for patients. In this respect, the report sets out how 'some clinicians need to be more confident with established good practice, such as skilled use of morphine and other opiate drugs'.¹⁸ Chapter 2 illustrated that an element in developing such confidence is to remove uncertainty surrounding the legal dimensions of the practice.

The Parliamentary and Health Services Ombudsman report was reviewed by the House of Commons Public Administration and Constitutional Affairs Committee.¹⁹ This included reactions to the report, consideration of existing plans, and recommendations for further action. The reactions to the report underlined how the identified failings were already known and the issue was the need to effectively respond. Prof Higginson stated that '[t]he report is very helpful but it does not

16 National Palliative and End of Life Care Partnership, 'Ambitions for Palliative and End of Life Care' (2015).

17 Parliamentary and Health Service Ombudsman, 'Dying Without Dignity' (Parliamentary and Health Service Ombudsman 2015).

18 Ibid. 24.

19 House of Commons Public Administration and Constitutional Affairs Committee, 'Follow-up to PHSO Report: Dying Without Dignity' (HC 432).

tell us what we did not know already. ... But the issue now is to respond to the report and take some action and change things.’²⁰ The solution advanced by Baroness Finlay was to propose legislation, namely, the Access to Palliative Care Bill 2015. This legislative approach to improving the standard of palliative and specialist palliative care garnered support from Dr Collins, Prof Higginson, and Prof Sir Mike Richards. Yet, it was ultimately rejected by the Government. The review recognised the Government’s unwillingness to countenance a legislative approach but stated that ‘it must now set out how it will ensure that necessary improvements will be achieved.’²¹ Subsequent Government action in this area has, in part, been informed and influenced by the publication of the Choice Review. Although it cannot be said that this introduces changes on par with those proposed by the Access to Palliative Care Bill.

The Independent Review of Choice in End of Life Care (the Choice Review), examined how the quality and experience of end of life care could be improved through expanding choice. Inevitably, choice will be constrained by the available resources, geographical limitations, and the knowledge of healthcare practitioners. The individual does not enjoy unrestricted choice at the end of life. Despite the report focusing on patient choice it is notable that there was no direct reference to the right of autonomy and the Mental Capacity Act 2005 was referenced once. This is in keeping with many of the previous reports and, in this vein, it was recognised that many of the challenges identified are not new. For instance, key themes emerging from the review included the discrepancy between preferred and actual place of death, and choice in relation to pain control and family involvement.

The Choice Review recommended that a ‘national choice offer’ for end of life care be established by April 2020. It was suggested that this choice offer be embedded in the NHS Constitution and that the offer be reflected in the NHS Choice Framework. The need for this is somewhat questionable as the NHS Constitution already set out that:

You have the right to be involved in planning and making decisions about your health and care with your care provider or providers, including your end of life care, and to be given information and support to enable you to do this. Where appropriate, this right includes your family and carers. This includes being given the chance to manage your own care and treatment, if appropriate.²²

Further to this, a House of Commons Health Committee report previously set out that ‘[t]he legal framework to support people’s choices and preferences for their

20 Ibid. 7. The Association for Palliative Medicine stated that problem was ‘not lack of awareness of the issues, but rather a lack of implementation.’

21 Ibid. 19.

22 Department of Health, ‘NHS Constitution for England’ (Department of Health 2015).

care is set out in the Mental Capacity Act 2005.²³ Consequently, a legislative framework already exists to protect choice. Although, the evidence presented to the House of Commons Health Committee suggested that the legislation is not well understood and was hindered by a lack of awareness.²⁴ Regardless, the recommendations of the Choice Review were broadly accepted by the Government.²⁵ The Government response also indicated that they would act in line with and build on the Ambitions for Palliative and End of Life Framework as well as the five Priorities for Care of the Dying Person.

Deficiencies in palliative and end-of-life care have proven to be constant since the publication of the Calman-Hine Report. Key themes include the commissioning of palliative care services, pain and symptom control, care planning, availability of care when and where needed, professional competencies, and funding. These themes are also documented in the 'National Care of the Dying Audit for Hospitals, England'.²⁶ In a majority of cases it was recognised that the patient was nearing the end of life but there was documented discussion with the patient in only 46% of cases.²⁷ Moreover, recorded discussion with the patient about artificial hydration as well as artificial nutrition occurred with only 17% of patients with capacity.²⁸ The audit also revealed that many relatives, 37%, thought the emotional support they received was only fair or poor, and 24% did not feel adequately supported during the final two days of the patient's life.²⁹ It is to be remembered that appropriate palliative care also provides support for these family members. Unfortunately, data released by the Care Quality Commission suggests that the palliative and end-of-life care provided in many facilities is far below the expected standard. Of 176 facilities, 8 were rated outstanding, 94 were good, 67 required improvement, and 7 were inadequate.³⁰ All of this serves to demonstrate the challenge of translating policy into effective practice.

The strategy and policy documents demonstrate the complex jigsaw of palliative care provision. There are a multitude of factors which inform and influence the standard of care yet, as noted at the outset, the legal framework was often at the periphery. The legal framework has an important normative role for both the patient and the healthcare professional. It establishes minimum standards of care, frames healthcare decision-making, and shapes professional practice. The Ambitions framework concentrated on the potential of local leadership to develop

23 House of Commons Health Committee, 'End of Life Care: Fifth Report of Session 2014–15' (HC 805) 23.

24 Ibid.

25 Department of Health, 'Our Commitment to You for End of Life Care: The Government Response to the Review of Choice in End of Life Care' (Department of Health 2016).

26 Royal College of Physicians, 'National Care of the Dying Audit for Hospitals, England' (Royal College of Physicians 2014).

27 Ibid. 8

28 Ibid.

29 Ibid. 9

30 S. Boseley, 'Four in 10 hospitals told to improve care for the dying' *The Guardian* (London 3 February 2016).

palliative care but this does not lead to consistency at a national level. Drawing on the approach of Baroness Finlay, perhaps it is time to utilise the influence of the law to greater effect if compelling change is to be brought about. The legal framework will not be a panacea for all issues but it should not be an overlooked factor in development. Indeed, the role of the legal framework for palliative care has been explicitly recognised in jurisdictions such as Italy,³¹ France,³² and New York State.³³

4.1.2 The standard setting function of the General Medical Council

The General Medical Council (GMC) is the statutory regulator for the medical profession in the UK. It is tasked with the protection of patients, setting standards for doctors, and overseeing doctors' education and training. Section 1B of the Medical Act 1983 sets out that the GMC is 'to protect, promote and maintain the health, safety and well-being of the public'.³⁴ One of the ways in which this is achieved is through their standard setting function. The core professional standards for medical practitioners are set out in 'Good Medical Practice'.³⁵ This guidance covers fundamental aspects of medical practice and is divided into four domains, namely: knowledge, skills, and performance; safety and quality; communication, partnership, and teamwork; and maintaining trust. In addition, specific guidance which addresses the challenges arising in end-of-life care has been published. This guidance is titled 'Treatment and care towards the end of life'³⁶ and it provides a framework for good practice when treating and caring for patients who are expected to die within the next 12 months. A significant departure from the guidance can result in a warning from the GMC and could put the doctor's medical registration at risk.

The guidance issued by the GMC on end of life care came into force on 1 July 2010. It is based on well-established principles such as equality and human rights, a presumption in favour of prolonging life, and a presumption of capacity. The guidance expands on the GMC's 'Good Medical Practice' document along with 'Consent: patients and doctors making decisions together'.³⁷ It replaced the

31 Law no. 38 of 15 March 2010; V. Ivone, 'Access to Palliative Care in the Italian Legal System' in S. Negri and others, *Advance Care Decision Making in Germany and Italy* (Springer 2013).

32 Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie.

33 Palliative Care Information Act 2011; Palliative Care Access Act 2011; A.B. Astrow and B. Popp, 'The Palliative Care Information Act in Real Life' (2011) 364 *New England Journal of Medicine* 1885.

34 Medical Act 1983, s. 1B.

35 General Medical Council, 'Good medical practice' (General Medical Council 2013).

36 General Medical Council, 'Treatment and care towards the end of life: good practice in decision making' (General Medical Council 2010).

37 General Medical Council, 'Consent: patients and doctors making decisions together' (General Medical Council 2008).

booklet titled 'Withholding and Withdrawing Life-Prolonging Treatments'.³⁸ Change was needed due to the enactment of the Mental Capacity Act 2005 and the publication of several reports that underlined failings in patient care. While the guidance is directed at doctors, the GMC recognise that it can also 'help patients and the public to understand what to expect of their doctors'.³⁹ The guidance can also inform other healthcare professionals contributing to multi-disciplinary care of the patient.⁴⁰

'Treatment and care towards the end of life' provides substantial guidance on issues including decision-making, clinically assisted nutrition and hydration, and cardiopulmonary resuscitation. The guidance is clearly informed by the legal framework including the Mental Capacity Act 2005 and applicable case law.⁴¹ Models of decision-making are addressed early in the guidance and contain a mix of practical steps along with considerations based on the Mental Capacity Act. The guidance seeks to displace medical paternalism in favour of patient autonomy. As such, doctors are to clearly communicate with the patient and/or their representative, engage with multidisciplinary teams involved in the care of the patient, and maintain a record of treatment and care decisions. Palliative care is referenced in the guidance and it establishes an overriding duty to 'give early consideration to the patient's palliative care needs'.⁴²

Early in the guidance it is stated that '[t]he most challenging decisions in this area are generally about withdrawing or not starting a treatment when it has the potential to prolong the patient's life'.⁴³ The challenge of such decisions was illustrated in earlier chapters of this work and these highlighted the added complications when palliative sedation is a factor. In addressing the decision to withhold or withdraw treatment the guidance states '[g]iven the uncertainties, you and others involved in the decision-making process may need reassurance about what is ethically and legally permissible, especially when deciding whether to withdraw a potentially life-prolonging treatment'.⁴⁴ It is questionable whether this reassurance is fully provided by the guidance.

The guidance notes that the evidence of benefits and burdens associated with clinically assisted nutrition and hydration is 'not clear-cut'.⁴⁵ It follows that the guidance emphasises the importance of communication, and discussion is to take account of cultural and religious views relevant to the patient. The assessment should consider nutrition and hydration separately; a distinction acknowledged in Chapter 2. Although the decision is to be based on an assessment of benefits, burdens, and risks, the patient's request will be determinative when factors are

38 General Medical Council, 'Withholding and withdrawing – guidance for doctors' (General Medical Council 2002).

39 GMC (note 36) 6.

40 Ibid.

41 Ibid. 76.

42 Ibid. 23.

43 Ibid. 9.

44 Ibid.

45 Ibid. 54.

finely balanced.⁴⁶ However, doctors are not under an obligation to provide treatment which would not be clinically appropriate. For adults without sufficient capacity the focus will be placed on whether the provision of clinically assisted nutrition and hydration would be of overall benefit. Key factors include whether treatment would prolong life or provide relief from symptoms. More specific guidance is provided based on the patient's prognosis. If the patient is expected to die in hours or days and it is judged that the burdens or risks outweigh the benefits of providing treatment then it will not normally be appropriate to commence or continue treatment. These are not to be single assessments but require regular review.⁴⁷

The guidance addresses many challenges raised at the end of life but does not directly address the practice of palliative sedation or how this practice impacts on the decision to withhold or withdraw treatment. In Chapter 1, research by Seale was cited which suggested a frequency of 16.5% for palliative sedation in the UK. This figure was based on end-of-life decisions between 2007 and 2008.⁴⁸ Decisions about palliative sedation were therefore often made in the UK at the time this GMC guidance was being developed. Yet, no practice specific guidance was issued; no reference to the identification of refractory symptoms. Instead it is necessary for doctors to draw on multiple sections of the guidance to frame medical practice in this area and there are shortcomings to this approach. Bell commented that 'the GMC has been notably concise about defensible administration of analgesia and sedatives at the end of life, despite the backdrop of extensive public, professional, political, and legal debate on "assisted suicide."'⁴⁹ As such, clear guidance on palliative sedation could have clarified decision-making in this area as well as underlining the legitimacy of the distinction between specialist palliative care practice and euthanasia.

4.1.3 The demise of the Liverpool Care Pathway

The Liverpool Care Pathway (LCP) has been discontinued but at one point it had a central role in guiding treatment and care practices for patients at the end of life. The European Pathway Association defined a care pathway as '[a] complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period.'⁵⁰ It is not however a set path establishing a requisite course of treatment. Although some healthcare professionals interpreted it as such.

The LCP served as a framework to provide a high quality of care to the dying patient in the last hours and days of life. The care pathway was developed by the

46 Ibid. 56.

47 Ibid. 59.

48 C. Seale, 'End-of-life decisions in the UK involving medical practitioners' (2009) 23 *Palliative Medicine* 198.

49 D. Bell, 'GMC guidance on end of life care' (2010) 340 *The BMJ* 3231.

50 European Pathway Association, 'Care Pathways' <<http://c-p-a.org/care-pathways/>> accessed 3 November 2017.

Royal Liverpool University Hospital and the Marie Curie Hospice in Liverpool. The LCP document outlined an holistic form of care with sections addressing the initial assessment, ongoing assessment, and care after death. In addition, the document considers the physical, psychological, social, and spiritual care of the person. The model was not only applicable to hospice care but was intended to be used to improve the standard of palliative and end-of-life care wherever it was being provided. In this regard, Ellershaw and Murphy noted that '[t]he LCP generic document is only as good as the teams using it.'⁵¹ The multidisciplinary teams which drew on the LCP were generally 'inexpert in palliative care'⁵² and reports began to emerge that the LCP was not applied in a consistent manner leading to poor end of life care.

These reports emerged through the media and significantly harmed the reputation of the LCP. At the time it was described by the *Daily Mail* as 'a pathway to euthanasia',⁵³ and links to financial incentives were suggested. In response, a review chaired by Baroness Julia Neuberger was established. This resulted in the publication of 'More Care, Less Pathway: A Review of the Liverpool Care Pathway'.⁵⁴ It acknowledged that the LCP facilitated good care of the person at the end of life in circumstances where the pathway was well used. Nevertheless, the review also identified many instances where use of the LCP was linked to a poor quality of care. A total of 44 recommendations were made, one of which was the phasing out of the LCP within six to twelve months.

The review was wide-ranging and examined issues of environment, accountability, communications, and training among others. Hydration and nutrition was a consistent issue arising in the submissions from relatives and carers. There were failings in the provision of oral hydration as well as clinically assisted hydration. The review determined that 'far too often the LCP advice on these is not being followed'.⁵⁵ As such, the failure was often on the part of the healthcare professional rather than the LCP.⁵⁶ In relation to sedation, it was evident that greater discussion with all parties involved was required. This would encourage the rationale behind sedation and pain relief to be further explored by the healthcare professional.

The vacuum left by the Liverpool Care Pathway was subsequently filled by guidance titled 'One Chance to Get it Right'.⁵⁷ This was published by the

51 J. Ellershaw and D. Murphy, 'What is the Liverpool Care Pathway for the Dying Patient?' in J. Ellershaw and S. Wilkinson (eds), *Care of the Dying: A Pathway to Excellence* (2nd edn, Oxford University Press 2011) 15.

52 Independent Review of the Liverpool Care Pathway, 'More Care: Less Pathway: A Review of the Liverpool Care Pathway' (2013) 12.

53 J. Stevens, 'A pathway to euthanasia? Family revive father doctors ruled wasn't worth saving' *Daily Mail* (13 February 2013).

54 Independent Review of the Liverpool Care Pathway (note 52).

55 Ibid. 7.

56 C. Regnard, 'The demise of the Liverpool Care Pathway: should we ban the highway code because of bad drivers?' (2014) 43(2) *Age and Ageing* 171.

57 Leadership Alliance for the Care of Dying People, 'One Chance to get it Right' (LACDP 2014); N. Sykes, 'One Chance to Get it Right: understanding the new guidance for care of the dying person' (2015) 115(1) *British Medical Bulletin* 143.

Leadership Alliance for the Care of Dying People. This Alliance is composed of the Department of Health, NHS England, NICE, and national charities. The response of the Alliance to the LCP review was to establish the five Priorities for Care. In cases where it is thought that the patient has a prognosis of a few days or hours:

- 1 This possibility is recognised and communicated clearly, decisions made, and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
- 2 Sensitive communication takes place between staff and the dying person, and those identified as important to them.
- 3 The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
- 4 The needs of families and others identified as important to the dying person are actively explored, respected, and met as far as possible.
- 5 An individual plan of care, which includes food and drink, symptom control, and psychological, social, and spiritual support, is agreed, co-ordinated, and delivered with compassion.⁵⁸

These priorities demonstrate a focus on the individual wishes and needs of the patient. It therefore ensures the patient remains central to healthcare decision-making in this area. In the House of Commons Health Committee report on end of life care it was stated that '[e]very care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life.'⁵⁹ In addition to informing the work of healthcare professionals, these priorities are also to be embedded in commissioning processes. Good quality care is therefore not only about professional competencies but it also requires appropriate resources and supports to be made available.

4.1.4 The planning and commissioning of palliative care services

Clinical Commissioning Groups (CCGs) are a relatively new development as they were created following the Health and Social Care Act 2012 and replaced the Primary Care Trusts on 1 April 2013.⁶⁰ CCGs are clinically-led statutory NHS bodies which are tasked with the planning and commissioning of healthcare services in their local region. This is a continuous process and CCGs must respond to changes and developments at the local level. There are currently 211 CCGs in England and, owing to their role, they control a majority of NHS expenditure. Consequently, these bodies have a significant influence on the resources made available for palliative and specialist palliative care in any given location.

⁵⁸ LACDP (note 57).

⁵⁹ House of Commons Health Committee (note 23) 12.

⁶⁰ NHS Clinical Commissioners, 'About CCGs' <<https://www.nhscc.org/ccgs/>> accessed 3 November 2017.

The role of CCGs means that they are often addressed in strategy documents and there have been several calls for CCGs to provide greater clarity on palliative care provision. This has included the Access to Palliative Care Bill 2015, the Access to Palliative Care Bill 2017, and the House of Commons Health Committee on End of Life Care.⁶¹ Steps have also been taken by NHS England and the Royal College of General Practitioners in an attempt to better inform CCGs about the need for palliative care provision.⁶² NHS England published 'Commissioning person centred end of life care' as a 'supporting resource' but this was primarily aimed at generalist care.⁶³

The function of CCGs in commissioning services ultimately impacts on the availability of adequate pain and symptom control, access to out-of-hours services, and, significantly, it affects the protection of human rights in practice. Research conducted by Lancaster et al. suggests that there are considerable variations in the commissioning of palliative care.⁶⁴ This research was based on responses from 204 CCGs and addressed seven key themes. The funding of specialist palliative care services revealed a considerable divergence between CCGs, as the allocated budget ranged from £51.83 to £2329.19 per patient per annum. On patient accessibility to specialist palliative care beds, 77.9% commission 7-day admission to specialist palliative care beds with a majority, 74.85%, of beds provided by hospices and only 4.9–6.1% NHS provided. The commissioning of 24/7 specialist palliative care services differed substantially as did the provision of support teams. Only 31.37% of CCGs indicated that 7-day hospital acute pain control team services were commissioned, a majority of which only function during regular working hours. There are positive elements revealed by this study but it also highlights a 'postcode lottery'. Failings in this area ultimately impact on vulnerable members of the population. Lancaster et al. concluded that 'the provision of specialist palliative care is in need of a national framework to ensure that patients achieve good end-of-life care everywhere.'⁶⁵ The suggestion proposed by Baroness Finlay was to establish such a framework in legislation, a point which will be examined later in this chapter.

4.1.5 The contribution of the National Institute for Health and Care Excellence

The National Institute for Health and Care Excellence (NICE) is a Non Departmental Health Body with responsibility for the development of guidance and quality standards in social care. NICE is accountable to the Department of Health but the guidance and recommendations are formulated by independent

61 House of Commons Health Committee (note 23) 17.

62 Royal College of General Practitioners, 'RCGP Commissioning Guidance in End of Life Care' (2013).

63 NHS England, 'Commissioning person centred end of life care: A toolkit for health and social care' (NHS 2016).

64 H. Lancaster and others, 'Commissioning of specialist palliative care services in England' *British Medical Journal* [online first] 28 February 2017.

65 Ibid.

committees. NICE have set out guidelines and quality standards for palliative and end-of-life care. However, the effect of this guidance is somewhat tempered as the guidance is officially England only. In effect, Wales, Scotland, and Northern Ireland are outside its remit.

The work of NICE informs the treatments and drugs made available through the NHS.⁶⁶ These recommendations are evidence-based and outline the effectiveness and appropriateness of treatments. Of particular relevance to this discussion are the guidelines titled 'Improving supportive and palliative care for adults with cancer',⁶⁷ 'Palliative care for adults: strong opioids for pain relief',⁶⁸ and 'Care of dying adults in the last days of life'.⁶⁹ The role of NICE is such that it informs the work of CCGs as well as providing a framework for healthcare professionals. While the National Health Service Act 2006 along with the NHS Constitution suggests that CCGs are largely obliged to act in accordance with NICE guidance, this does not extend to healthcare professionals and they are not bound by the guidance.⁷⁰

Although the guidance is not compulsory, it was suggested by NICE that it 'should be taken into account by healthcare and other professionals when planning care for individual patients'.⁷¹ Unfortunately, such an approach does not encourage widespread consistency across palliative care providers. The most recent guidance on end of life care published by NICE is 'Care of dying adults in the last days of life'. This includes recommendations on identifying when people are nearing the end of life, communication and decision-making, assisted hydration, management of pain, and anticipatory prescribing. It was, in part, a response to concerns surrounding the Liverpool Care Pathway. These concerns related to lack of support from an experienced clinician in recognising that a person was dying, injudicious use of sedation, and issues around the withholding or withdrawal of treatment.

As the title of the guideline suggests, it addresses the clinical care of adults with a life expectancy of 2–3 days. The aim is to 'improve end of life care for people in their last days of life by communicating respectfully and involving them, and the people important to them, in decisions and by maintaining their comfort and dignity'.⁷² The guidance is aimed at general healthcare professionals rather than specialists in palliative care. In this respect, it was hoped that it would establish 'a baseline for standards of care in settings that specialise in caring for people who are dying'.⁷³ Two recommendations in this guideline will be briefly examined, namely maintaining hydration and pharmacological interventions.

66 Department of Health (note 22) 7 'You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you.'

67 NICE, 'Improving supportive and palliative care for adults with cancer' (NICE 2004).

68 NICE, 'Palliative care for adults: strong opioids for pain relief' (NICE 2016).

69 NICE, 'Care of dying adults in the last days of life' (NICE 2015).

70 *R(Rose) v Thanet Clinical Commissioning Group* [2014] EWHC 1182 (Admin).

71 NICE, 'How NICE Clinical Guidelines are Developed: An Overview for Stakeholders, the Public and the NHS' (NICE 2012) 7.

72 NICE (note 69) 4.

73 *Ibid.* 5.

The healthcare professional is to support the patient to take oral hydration if desired and capable of doing so. Practical care measures such as mouth and lip care are also highlighted in the guideline. As for clinically assisted hydration, this involves a discussion of the risks and benefits with the patient and those important to her. The guideline also includes details on the advice to be given including reference to potential problems, and uncertainty around prognosis due to provision or withholding of assisted hydration. This echoes previous discussion around the impact of artificial nutrition and hydration. Guidance on the management of pain is quite general, for example, '[i]f pain is identified, manage it promptly and effectively, and treat any reversible causes of pain'.⁷⁴ Part of the reason for this general level of guidance may be due to the publication in May 2012 of 'Palliative care for adults: strong opioids for pain relief'.

The guideline on strong opioids was revised in August 2016 and is aimed mainly at healthcare professionals. It addresses communication with the patient, starting strong opioids, and the management of nausea and drowsiness. Familiar guidance is provided around titration levels such as recommending that the dose be adjusted 'until a good balance exists between acceptable pain control and side effects'.⁷⁵ Like the other NICE guidelines there is a considerable level of detail. However the issue of enforceability is a significant shortcoming.

NICE pathways make the exploration and identification of relevant guidance all the clearer. However, the failings identified in the reports cited above indicate that NICE guidance is not completely effective in influencing CCGs. In turn, if CCGs fail to provide appropriate resources then the care which can be provided is limited. The lack of enforceability against healthcare professionals is in some respects regrettable as it deprives the guidelines of any coercive force. It is therefore not wholly surprising to note recent attempts to use legislation as a tool to bring about change in palliative and specialist palliative care.

4.1.6 An emerging legislative response to palliative care provision

There have been multiple attempts to enact legislation which directly addresses aspects of palliative care provision. The proposed bills rarely progress past a third reading and have encountered consistent government opposition. These bills have sought to improve palliative care provision in the UK through measures aimed at palliative care training, research priorities, palliative care leave, national funding, and pain and symptom control. One of the first pieces of legislation to reference palliative care was the Assisted Dying for the Terminally Ill Bill 2005. This included a requirement that both the attending and consulting physician inform the patient of palliative care services. A palliative care specialist was to attend the patient to inform him/her of the benefits of palliative care.⁷⁶ In the interim, there have been more focused attempts to legislate for palliative care, including the

⁷⁴ Ibid. 15.

⁷⁵ NICE (note 68) 9.

⁷⁶ Assisted Dying for the Terminally Ill Bill 2005, s.2(2).

Palliative Care Bill 2006, the Palliative Care Bill 2008, the Access to Palliative Care Bill 2015, and the Access to Palliative Care Bill 2017.

Palliative Care Bill 2006

The Palliative Care Bill 2006 was a private members bill introduced by Baroness Finlay of Llandaff. It received support from the Motor Neurone Disease Association, the British Heart Foundation, Marie Curie Cancer Care, Sue Ryder Care, Help the Hospices, and the National Council for Palliative Care. The Bill sought to place an obligation on healthcare commissioners and providers in England and Wales to take steps towards ensuring that appropriate specialist palliative care services are in place for terminally ill people and that generalist services are capable of providing care which satisfies the general palliative care needs of patients in the broader healthcare system. The Bill also required arrangements to facilitate palliative care research, to produce an annual report, and to develop palliative care strategies.

Baroness Finlay stated that these requirements were not new as the Department of Health had repeatedly called on health authorities to develop palliative care strategies.⁷⁷ Yet, these strategies were still lacking at the time of this Bill.⁷⁸ In section 1 of the Palliative Care Bill it sets out that: '[t]he appropriate authority must ensure the provision of palliative care to every person with a terminal illness to such extent as is necessary to meet all such persons' reasonable requirements.'⁷⁹ The use of the term 'reasonable requirements' was intended to reflect the distinction between need and demand. Baroness Finlay was cognisant of the limits that exist but argued that 'the principle of justice dictates that each person should have the best care within the resources available and that there must be an equitable distribution of resources.'⁸⁰ To this end, the Bill would have promoted greater consistency in the funding of specialist palliative care services thereby allowing for better long-term service planning which would ultimately benefit the patient.⁸¹

Palliative Care Bill 2008

Central to this private members bill was the right to choose where to receive palliative care.⁸² Section 1 of the Palliative Care Bill permitted the patient to

77 HL Deb 23 February 2007, col 1273 'Between 1987 and 1999, the Department of Health issued at least eight circulars or executive letters exhorting health authorities to develop palliative care strategies, but co-ordinated strategies have not happened across the board in 20 years.'

78 Ibid. 'I have contacted all 10 strategic health authorities in England, but I have received very varying responses to my request for their strategies, drawing a blank on four of them.'

79 Palliative Care Bill 2006, s.1(1).

80 HL Deb 23 February 2007, col 1276.

81 Ibid. 'palliative care has not become mainstreamed and specialist palliative care services do not know from one year to the next whether there will be a contract for their services or whether they will, in effect, be closed down.'

82 Private members' bill sponsored by Mrs Caroline Spelman.

specify whether they wanted to receive specialist palliative care in an NHS hospital, in a hospice, a care home, in their own home, or in the home of another named individual.⁸³ Accordingly, the Bill required the relevant NHS authority to take all reasonable steps to fulfil such requests.

The preferred place of death is a regular issue to arise in questions about the quality and availability of palliative care. It is about more than patient autonomy and instead reflects the standard of palliative care provision across a range of providers. It was suggested that this Bill was necessary as the commissioning and provision of palliative care is ‘patchy’.⁸⁴ The proposed Palliative Care Bill did not address substantive issues but instead sought to address a specific aspect of patient autonomy. It is therefore questionable whether any significant changes would have been brought about were this Bill to have advanced beyond a second reading.

Access to Palliative Care Bill 2015

The Access to Palliative Care Bill was a departure from the preceding bills as it was more comprehensive and ambitious in its aims. This private members bill was introduced by Baroness Finlay of Llandaff and addressed palliative care support, the duty to commission palliative care services, education and training, research, and the Care Quality Commission. Similar to the preceding bills, this Bill was motivated by failings in palliative care which had been catalogued by the national audit conducted by the Royal College of Physicians, and the House of Commons Health Committee report on end-of-life care. The problems were consistent over time and Baroness Finlay suggested that this legislative approach was ‘a chance to finally get it right for all. It meets the recommendations that appear consistently in reports’.⁸⁵ As such, it was intended that the Bill would contribute to narrowing the gap in hospice provision between wealthy and poorer areas as well as ensuring equality of care for patients with a non-cancer diagnosis.

During the debates it was suggested that clinical commissioning groups are struggling to respond adequately and, consequently, ‘[t]hey need a clear, simple template to bring up the standard of services.’⁸⁶ Section 2 of the Access to Palliative Care Bill set out that ‘[a] clinical commissioning group must make arrangements so as to ensure that specialist palliative care services are available to people with palliative care needs for whom the clinical commissioning group is responsible’.⁸⁷ The section goes on to list the various arrangements which include:

- a support to people with complex palliative care needs in their own homes, in hospitals, in hospices, in care homes and elsewhere within the local community;

83 Palliative Care Bill 2008, s.1(1).

84 HC Deb 24 April 2009, col 517.

85 HL Deb 23 Oct 2015, col 909.

86 HL Deb 23 Oct 2015, col 909.

87 Access to Palliative Care Bill 2015, s.2(1).

- b direct admission of people with palliative care needs to hospice beds, including on an urgent basis when reasonably required;
- c support to other health and social care providers who are caring for people with palliative care needs;
- d specialist palliative care and hospice services which are available on every day of the week;
- e sufficient specialist professionals who are available to deliver services to meet all reasonable requirements;
- f sufficient equipment for any specialist professionals to enable the delivery of services to meet all reasonable requirements;
- g telephone advice from a healthcare professional who is qualified as a specialist in palliative care which is available at all times to professionals providing care to people with palliative care needs;
- h facilities to enable healthcare professionals to access essential medication at all times for palliative care patients being cared for in their own homes;
- i a point of contact which is available at all times for people with palliative care needs who are being cared for in their own home or usual place of residence, and those important to them, in the event that such persons are unable to access their usual sources of support; and
- j appropriate systems to ensure that appropriate information about people who have palliative care needs can be made available with the consent of the person to relevant health and social care providers and to the ambulance services.⁸⁸

At first instance, this appears like an onerous list of demands. However, these merely reflect points which have been called for in multiple reports but which have not been delivered in a consistent manner across the country as evidenced by the ‘postcode lottery’.⁸⁹

The Access to Palliative Care Bill also addressed the education and training of healthcare professionals. Section 3 of the Bill set out that Health Education England must establish training requirements for defined areas of particular relevance to palliative care. These included communication skills, and ways to support families and carers. Although palliative sedation is not directly referenced in the Bill, section 3(1)(a) required training in ‘the importance of pain control’ and stated ‘that neglect of a person’s analgesic requirements can be a failure of a duty of care’.⁹⁰ In Chapter 3 the significance of the Mental Capacity Act was outlined while in this chapter the poor understanding of the Act in practice was highlighted. It is therefore significant that the Access to Palliative Care Bill also required training in the ‘the importance of the Mental Capacity Act 2005 with relation to people with palliative care needs’.⁹¹

88 Access to Palliative Care Bill 2015, s.2(2).

89 HL Deb 23 Oct 2015, col 910.

90 Access to Palliative Care Bill 2015, s.3(1)(a).

91 Access to Palliative Care Bill 2015, s.3(1)(c).

In sum, this Bill would support informed care, greater research, and encourage increased co-ordination between healthcare services. Nonetheless, it is to be questioned whether a legislative approach is appropriate. Legislation can prove rigid and it leaves little room for autonomy at the local level. It may also result in other areas of healthcare seeking to establish their requirements on a statutory basis. Baroness Finlay was adamant that such a precedent would not be set as '[n]o other area of healthcare has 100% certainty'.⁹² Despite this, the Government was not in support of a legislative approach to ameliorate palliative care provision. There are three points that can be highlighted in the comments of Lord Prior of Brampton, the Parliamentary Under-Secretary of State Department of Health. First, Lord Prior suggested that the issues in the Bill are best addressed by clinicians in consultation with patients and their carers. Unfortunately, this does little to address issues of education or inadequate resource provision. It also pays little attention to the good practice developed in Wales on which the Bill is based.⁹³ The second point is the suggestion that 'a top-down, central directive, be it through legislation or from another source, can interfere with best-practice decision-making'.⁹⁴ Linked with this is concern for local autonomy as provided for in the Health and Social Care Act 2012. The Government wished to allow space for local innovation to emerge yet the multiple reports clearly indicate inconsistent palliative care provision and areas lacking appropriate palliative care resources.⁹⁵ Baroness Finlay noted that the support for research contained in the Bill would actually promote rather than stifle developments and that it would 'make sure that those who provide specialist palliative care have to keep up to date with what is going on and participate in research'.⁹⁶ The final point advanced by Lord Prior concentrated on the responsibilities of Health Education England. Although this body indicated support for the Access to Palliative Care Bill, Lord Prior commented that the Bill would undermine its role and responsibilities. The Bill was subsequently defeated but it signalled a significant step towards the use of legislation as a tool for the promotion of palliative care.

Access to Palliative Care Bill 2017

The defeat of the Access to Palliative Care Bill 2015 did not prevent Baroness Finlay from introducing the Access to Palliative Care Bill 2017. The 2017 Bill has clearly been informed by previous debates and seeks to stimulate the contribution of CCGs in the provision of palliative care services. A narrower approach is evident

92 HL Deb 23 Oct 2015, col 911.

93 HL Deb 23 Oct 2015, col 944.

94 HL Deb 23 Oct 2015, col 943.

95 HL Deb 23 Oct 2015, col 917–918. Lord Davies of Stamford, 'Some people might think that it is too prescriptive, that it overrides local initiative and clinical commissioning groups and forces everyone into the same Procrustean bed, but there will always be a trade-off between having some local autonomy in the health service and having a national health service and avoiding a postcode lottery.'

96 HL Deb 23 Oct 2015, col 944–945.

in the 2017 Bill as it drops the provisions on research, and education and training. Moreover, the duty to commission palliative care services is replaced with a duty to produce a strategy on the provision of palliative care support. Arguably, this Bill navigates the criticism of previous Bills and its modest aspirations may result in a greater chance of securing Government support.

Section 2 of the Access to Palliative Care Bill 2017 stipulates that the strategy should include:

- a the expected palliative care needs of adults and children in their area;
- b how the expected palliative care needs will be met;
- c under what circumstances specialist palliative care services will be provided and how; and
- d the methods of data collection and reporting.⁹⁷

The preparation and publication of the strategy is not a once-off requirement as it is to be reviewed and revised as necessary, and republished at least once every three years. At the time of writing, the date was still to be set for the second reading of the Bill. It would seem that it is only a matter of time before legislation directly addressing the provision of palliative care is enacted. The legislative framework cannot remain neglected indefinitely.

4.2 The legal framework for palliative care in Ireland

There are considerable similarities in the provision of palliative care in Ireland and in England and Wales. The voluntary sector in Ireland has also been a driving force behind the development of palliative and specialist palliative care. Furthermore, the Irish legal framework for palliative care provision is similarly fragmented. There is little relevant legislation addressing aspects of palliative and end-of-life care. Assisted suicide is prohibited under section 2(2) of Criminal Law (Suicide) Act 1993. While section 14(1) of the Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009 requires written operational policies and protocols to be put in place for end-of-life care in designated centres.⁹⁸ Applicable case law is limited and has been referenced in Chapters 2 and 3.⁹⁹ These cases have demonstrated the importance of protecting human rights, the possibility of treatment withdrawal, respect for advance decisions, and the prohibition on assisted suicide in Ireland. Moreover, *Fleming v Ireland* underlined the importance of clarity in the legal status of specialist palliative care practices. Beyond this, the legal framework is composed of professional guidelines and may be informed by the guidance of representative bodies and non-governmental organisations.

⁹⁷ Access to Palliative Care Bill 2017, s.2(2).

⁹⁸ Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009, s.14(1).

⁹⁹ *Ward of Court (withholding medical treatment) (No 2), Re*, [1996] 2 IR 79; *Fleming v Ireland & Ors* [2013] IESC 19.

This section will outline the reports and strategy documents of particular relevance to palliative care in Ireland. It will then turn to consider the standards and guidance published by the regulators of the healthcare profession in Ireland, namely the Irish Medical Council (IMC) and the Nursing and Midwifery Board of Ireland. The final element will be to examine the guidance of the Irish Association of Palliative Care (IAPC). Although not directly enforceable, IAPC guidance serves to inform local policy and assist in defining best practice.

4.2.1 A framework for palliative care development

The contribution of the voluntary sector was illustrated in Chapter 1. Voluntary groups were crucial in developing palliative care capacity and have had a significant influence on national policy. The Irish Hospice Foundation published a majority of the substantial reports on palliative care in the jurisdiction. This includes ‘The Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland’,¹⁰⁰ ‘Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks’,¹⁰¹ and ‘Access to Specialist Palliative Care Services and Place of Death in Ireland’.¹⁰²

Many of the national strategies have not had palliative care as a central theme but have instead included palliative care as part of a broader healthcare strategy. This is illustrated by several strategy documents published by the Department of Health, such as ‘The National Cancer Strategy’,¹⁰³ ‘The Primary Care Strategy’,¹⁰⁴ ‘Cancer Control Strategy’,¹⁰⁵ and ‘The National Positive Ageing Strategy’.¹⁰⁶ Policy documents have also been published by the Department of Health and the Health Service Executive. Among which the report of the National Advisory Committee on Palliative Care in 2001 was particularly significant.¹⁰⁷ This was a wide-ranging report and issued recommendations on specialist palliative care, quality and standards, communication, and the organisation of services.

More recently, a 2014 Joint Committee on Health and Children produced a report on end of life and palliative care in Ireland. This report examined specialist palliative care provision, the importance of a national strategy, financial resources, and calls for legislative change to underpin the ‘Quality Standards for End of Life

100 Irish Hospice Foundation, ‘A baseline study on the provision of hospice/specialist palliative care services in Ireland’ (IHF 2006).

101 Irish Hospice Foundation and Health Service Executive, ‘Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks’ (IHF 2008).

102 Irish Hospice Foundation, ‘Access to Specialist Palliative Care Services and Place of Death in Ireland’ (IHF 2013).

103 Department of Health, ‘The National Cancer Strategy’ (DOH 1996).

104 Department of Health, ‘The Primary Care Strategy’ (DOH 2001).

105 Department of Health, ‘The Cancer Control Strategy’ (DOH 2006).

106 Department of Health, ‘The National Positive Ageing Strategy’ (DOH 2013).

107 Department of Health and Children, ‘Report of the National Advisory Committee on Palliative Care’ (Department of Health and Children 2001); See also Department of Health, ‘Palliative Care For Children With Life-Limiting Conditions In Ireland – A National Policy’ (DOH 2010).

Care' in hospitals.¹⁰⁸ Such a legislative change would have made compliance with the standards mandatory. Despite this, policy on palliative care in Ireland continues to be mainly developed at a local level. Regardless of jurisdiction, a reliance on local policy means that uniformity across providers of palliative care will not be easily achieved.

4.2.2 The Irish Medical Council

The IMC was established by the Medical Practitioners Act 1978.¹⁰⁹ It is the regulator of the medical profession in Ireland and is currently governed by the Medical Practitioners Act 2007.¹¹⁰ Under the 2007 Act it is set out that the purpose of the IMC is 'to protect the public by promoting and better ensuring high standards of professional conduct and professional education, training and competence among registered medical practitioners.'¹¹¹ This underlines how the protection of the public is closely tied to professional conduct and competence on the part of the medical practitioner. In line with this, the IMC is required to set out appropriate standards of practice for doctors including the publication of appropriate guidance on matters of relevance to professional conduct and ethics for registered medical practitioners in Ireland.¹¹² On this point, the Guide to Professional Conduct and Ethics is not binding in law but is relevant for the regulation of the medical profession and the establishment of what constitutes good ethical medical practice.

Guide to Professional Conduct and Ethics for Registered Medical Practitioners

Professional guidance issued by the IMC has evolved over the years, particularly the guidance on aspects of end-of-life care. This reflects the development of palliative care, and demonstrates an evolving awareness of what good end-of-life care means and involves. The first IMC professional standards were published in 1981 and the relevant guidance was set out under the heading of 'euthanasia'.¹¹³ The 1981 guidance set out that '[w]here death is imminent it is the doctor's responsibility to take care that a patient dies with dignity and as little suffering as possible.'¹¹⁴ The second,¹¹⁵ third,¹¹⁶ and fourth edition¹¹⁷ of the IMC Guide to Ethical Conduct

108 Houses of the Oireachtas Joint Committee on Health and Children, 'Report on End of Life and Palliative Care in Ireland' (July 2014).

109 Medical Practitioners Act 1978.

110 Medical Practitioners Act 2007.

111 Medical Practitioners Act 2007, s.6.

112 Medical Practitioners Act 2007, s.7(2)(i).

113 The Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (Dublin 1981) 15.

114 Ibid.

115 Irish Medical Council, 'Constitution and Functions: A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (2nd edn, Dublin 1984) 22.

116 Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (3rd edn, Dublin 1989) 33–34.

117 Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (4th edn, Dublin 1994) 43.01.

and Behaviour continued to address end-of-life care under the heading of 'euthanasia'. No change was made to the substantive content of the guidance during this time. It was not until the fifth edition of the guidance that the heading 'euthanasia' was replaced with the term 'the dying patient'. The use of a more ethically neutral phrase signalled a more open approach to caring for the patient at this point in their life and a small number of changes were made to the text of the guidance. IMC guidance further developed with the sixth edition of the Guide to Ethical Conduct and Behaviour. However, it was the seventh edition of the guide which demonstrated a substantive shift by providing more detailed guidance than what had come before.

In 2016 the eighth edition of the Guide to Professional Conduct and Ethics for Registered Medical Practitioners was published. General guidance is provided on consent, capacity, the provision of information, the timing of the consent process, and the refusal of treatment. Donnelly suggests that the Guide to Professional Conduct 'represents the beginnings of a patient-centred approach to dying'.¹¹⁸ However, this is not to suggest that it provides a wholly comprehensive framework. On this point, it is suggested that the Guide 'still leaves many questions unresolved ... The Guide is also limited in terms of requirements for, and advice regarding, a more active approach to listening to patients who are confused, distressed or have limited capacity'.¹¹⁹ Failings to fully engage with the patient in practice have also been noted in research by Quinlan and O'Neill,¹²⁰ as well as O'Shea et al.¹²¹

Specific guidance is provided on end-of-life care which addresses communication with the patient, decisions about the provision of treatment, and pain management. This is not step-by-step guidance but is intended to be drawn on in combination with a doctor's professional skill and judgement. Communication is vital for ensuring the patient is able to make informed decisions in relation to their healthcare. Medical practitioners are to be sensitive in the provision of information and ensure that both the patient and their family have a 'clear understanding of what can and cannot be achieved'.¹²² The Guide also recommends that information about possible palliative care options be communicated to the patient.

The Guide provides that medical practitioners are under no obligation to provide artificial nutrition and hydration where it is judged that it would be 'unlikely to work; or might cause the patient more harm than benefit; or is likely to cause the patient pain, discomfort or distress that will outweigh the benefits it may bring'.¹²³ Pain and symptom control is also addressed at a general level and

118 M. Donnelly, 'Patient-centred Dying: The Role of Law' in M. Donnelly and C. Murray (eds) *Ethical and Legal Debates in Irish Healthcare* (Manchester University Press 2016) 226

119 Ibid.

120 C. Quinlan and C. O'Neill, *Practitioners' Narrative Submissions* (IHF 2008).

121 E. O'Shea and others, *End-of-Life Care for Older People in Acute and Long-Care Stay Settings in Ireland* (IHF 2008).

122 Irish Medical Council, 'Guide to Professional Conduct and Ethics for Registered Medical Practitioners' (8th edn, Dublin 2016) 33.

123 Ibid. 33–34.

provides that patients should receive ‘appropriate pain management and relief from distress’.¹²⁴ No mention is made of refractory symptoms, questions of timing, or how psychological distress is to be addressed. As such, the IMC Guide to Professional Conduct and Ethics is of limited guidance for palliative and specialist palliative care.

It is not expected that IMC guidance would be able to address every aspect of medical practice in detail. However, this is an area of care, and a medical specialty, which a majority of people will engage with at some point. General guidance leaves medical practitioners to rely on concepts such as the doctrine of double effect. This does not promote consistency between doctors or with other healthcare professionals.

4.2.3 The Nursing and Midwifery Board of Ireland

The Nursing and Midwifery Board of Ireland was established by the Nurses Act 1950.¹²⁵ It is the regulatory body of the nursing profession in Ireland and is governed by the Nurses and Midwives Act 2011.¹²⁶ The Nursing Board occupies a role similar to the IMC in defining standards of professional conduct.¹²⁷ Accordingly, the Board has published ‘The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives’¹²⁸ (Code of Professional Conduct). In addition, guidelines for nurse prescribers,¹²⁹ and guidance for nurses working with older people have been published by the Board.¹³⁰ It can be suggested that the guidance issued by the Nursing Board demonstrates a greater engagement with the legal framework than the IMC guidance and this is seen throughout these documents.

Five principles underpin the Code of Professional Conduct, namely, respect for the dignity of the person, professional responsibility and accountability, trust and confidentiality, quality of practice, and collaboration with others. These principles serve to guide the interaction between the nursing profession, patients, and other healthcare professionals. The Code of Professional Conduct therefore acts to ‘show the attitudes and behaviours that members of the public have the right to expect from nurses’.¹³¹ Of the principles which underpin the Code of Professional

124 Ibid. 34.

125 Nurses Act 1950.

126 Nurses Act 1985.

127 Nurses and Midwives Act 2011, s.8.

128 Nursing and Midwifery Board of Ireland, ‘The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives’ (NMBI 2014).

129 Nursing and Midwifery Board of Ireland, ‘Collaborative practice agreement for nurses and midwives with prescriptive authority’ (4th edn, NMBI 2016); An Bord Altranais, ‘Practice Standards for Nurses and Midwives with Prescriptive Authority’ (September 2010).

130 Nursing and Midwifery Board of Ireland, ‘Professional Guidance for Nurses Working with Older People’ (2nd edn, November 2015).

131 NMBI (note 128) 9.

Conduct it is ‘respect for the dignity of the person’ which is of most relevance to palliative care due to the values and standards of conduct it requires of the nurse.

Respect for the dignity of the person

At the outset, this principle is grounded in law as it is drawn from the Universal Declaration of Human Rights. The values and standards underpinning this principle are informed by the European Convention on Human Rights, the Irish Constitution, and the Equal Status Acts. It illustrates how the care of the patient is underpinned by a broad range of human rights, as was highlighted in Chapter 3. As such, the Code provides detail on values, standards of conduct, and supporting guidance in relation to respecting the dignity of the patient.

Values concentrate on respecting and defending dignity. Emphasis is placed on the right to self-determination. A key element of this is the requirement of informed consent. The standards of conduct for respecting the dignity of the person reflect the values set out in the Code of Professional Conduct. Specific reference is made to end-of-life care, and nurses are to ‘support the person to die with dignity and comfort’.¹³² In the draft edition of the Code to Professional Conduct it was suggested that the nurse should ‘seek to understand how the person views dignity and provide care that tries to meet their needs’.¹³³ This may have been difficult to achieve in practice and was not included in the final edition. In any case, the nurse practitioner is to communicate effectively with the patient, respect advance healthcare directives, and promote patient autonomy. Supporting guidance addresses advance care directives and patient consent. Communication and information sharing has an important role in facilitating patient consent and is reflected in the guidance. A need for flexibility is recognised in the guidance and it provides that the level of information ‘will depend on the urgency, complexity, nature and risks associated with the intervention’.¹³⁴ This is not drawn out in more detail and, consequently, a subjective approach will be required from the nurse in determining the information and the nature of the discussion to take place with the patient. Nonetheless, the Code of Professional Conduct and Ethics is a positive step in providing greater guidance for nurses practising in Ireland.

Professional guidance for nurses working for older people

Aspects of ‘Working with Older People’ are of relevance for the provision of palliative care. The objectives of this document include providing professional guidance for nurses engaged in caring for the older person across all healthcare settings, and providing ‘a nursing framework for end of life care that embraces living and dying as part of the normal care structure and processes in all care

132 Ibid. 12.

133 Nursing and Midwifery Board of Ireland, ‘Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives’ (October 2013) 8.

134 NMBI (note 128) 15.

settings'.¹³⁵ This guidance was motivated by the projected increase in the older population, and the level of care needed to respond to the complex needs of the older person.

The professional guidance sets out standards on person-centred holistic care, therapeutic relationship, care environment, quality of care, professional development, and end-of-life care. The guidance on end-of-life care underlines the importance of protecting and promoting the older person's human rights and recognises that this requires nurses to 'be guided by, and work within, a legal framework'.¹³⁶ The importance of a clear legal framework for palliative and specialist palliative care is central to this work and has been recognised and highlighted by several stakeholders in patient care.¹³⁷ In this respect, it is positive that the Nursing and Midwifery Board recognise the role and impact which an appropriate legal framework can have for both the healthcare professional and the patient.

The standard on end-of-life care requires that '[t]he older person receives comprehensive, compassionate end of life care that is person-centred and responds to the older person's unique needs and respect for his/her wishes'.¹³⁸ The guidance also acknowledges the broad remit of palliative care and its potential for use earlier in the disease trajectory. It demonstrates an awareness of the role of the palliative care approach, general palliative care, and specialist palliative care. Nonetheless, the guidance refrains from addressing the complex issues arising in specialist palliative care such as palliative sedation and the withdrawal of artificial nutrition and hydration. These are practices which remain without clearly defined professional standards for nurses and therefore lack an appropriate legal framework. This is especially significant due to changes in professional competencies such as the nurse's prescriptive authority.

Nurses with prescriptive authority

It is a relatively recent development that certain nurses have taken on the responsibility of prescribing medication. The basis of a nurse's prescriptive authority is based on a dual framework of professional standards and medicines legislation. The main legislation providing for nurses prescriptive authority is the Irish Medicines Board (Miscellaneous Provisions) Act 2006,¹³⁹ the Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations 2007¹⁴⁰ and the

135 NMBI (note 130) 5.

136 Ibid. 13;

137 N. O'Leary and E. Tiernan, 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers' (2008) *Palliative Medicine* 77; K. McKeown and others, 'Dying in Hospital in Ireland: Nurse and Doctor Perspectives, Report 2' (Irish Hospice Foundation 2010).

138 NMBI (note 130) 13.

139 Irish Medicines Board (Miscellaneous Provisions) Act 2006.

140 Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations 2007, S.I. 201 of 2007.

Misuse of Drugs (Amendment) Regulations 2007.¹⁴¹ These set out requirements for the nurse to be able to prescribe and the conditions for prescribing. The Nursing and Midwifery Board has issued guidelines for nurse prescribers, namely the 'Practice Standards and Guidelines for Nurses and Midwives with Prescriptive Authority'¹⁴² as well as the 'Collaborative Practice Agreement for Nurses and Midwives with Prescriptive Authority'.¹⁴³

'Practice Standards for Nurses and Midwives with Prescriptive Authority' includes standards on clinical decision-making, communication and history taking, documentation, continuing professional development, and continued competency. The standards recognise that the nurse prescriber may prescribe drugs for end-of-life care but merely lists the types of drug suitable for palliative care and their route of administration. There is no guidance addressing appropriate levels of sedation or the identification of refractory symptoms. The overall effect is that for specialist palliative care the nurse prescriber has an increased role which is complicated by the lack of clear guidelines.

4.2.4 Diverging standards and practice

While both the IMC and the Nursing Board have updated their professional guidance in recent years it is not clear whether they have fully addressed underlying issues in palliative care provision. A national audit of end-of-life care in hospitals in Ireland was conducted in 2008. This was prior to the publication of the updated guidance. The audit demonstrated differences in how doctors and nurses perceived end-of-life care. The difference was demonstrated by a '48% response agreement on whether a patient was in pain all or most of the time'¹⁴⁴ while a similar level of agreement was seen in relation to symptom management.¹⁴⁵ Decisions on palliative care and specialist palliative care were examined separately in the report. It was shown that palliative care is of a high standard, but there is a lack of clarity about what decisions were made and considerably more disagreement around the frequency and management of the patient's symptoms.¹⁴⁶

It is significant that healthcare professionals appeared reluctant to withhold or withdraw treatment, even in circumstances where the death of the patient was expected.¹⁴⁷ It was suggested that this may be due to 'the absence of clear practice guidelines'.¹⁴⁸ This situation hampers the consistent protection of patients' human

141 Misuse of Drugs (Amendment) Regulations 2007, S.I. 200 of 2007.

142 An Bord Altranais (note 129).

143 NMBI (note 129).

144 McKeown (note 137) 28.

145 Ibid. 29 'The level of agreement between the responses of nurses and doctors on symptom management falls to 42%, on average, and indicates that, in the majority of cases, there is no agreement on whether the patient was kept comfortable.'

146 Ibid. 30–31.

147 Ibid. 30.

148 Ibid. 31.

rights as there is likely to be different approaches to palliative care adopted by different healthcare providers.

There were notable differences in the perception of doctors and nurses as to whether a patient had received specialist palliative care. Doctors believed 22% of patients had received specialist palliative care compared to the nurse's response of 32%.¹⁴⁹ The knowledge of specialist palliative care practices can also be questioned as a result of a response that in more than a quarter of cases, 26% according to nurses 29% according to doctors, it is not clear whether specialist palliative care would have been of benefit to the patient.¹⁵⁰ These professions work closely in the provision of specialist palliative care and it is important that they share a common understanding of palliative care practices. Inconsistency and ambiguity ultimately impacts on the care of the patient.

No categorical explanation for the differences was provided but several interpretations of the data were put forward. For instance, it was suggested that:

there is not a common understanding of what specialist palliative care actually means; that there is lack of information about the role of specialist palliative care; that the palliative care needs of these patients were not been properly assessed; that nurses and doctors have different perceptions of when a patient requires a specialist palliative care service; that there is no systematic procedure for calling upon the expertise of the specialist palliative care team when a diagnosis of dying is made.¹⁵¹

There is no single solution to address all of these issues but professional standards and guidance can have a considerable bearing on the type of care offered. The guidance discussed above provides more detail than previous standards. In particular, the Nursing Board has underlined the significance of palliative care. Yet, this has not been done to the same degree by the IMC and much is left to the knowledge and skill of the healthcare professional. The concern therefore is that these professions, which are engaged in multidisciplinary care of the patient, will move further apart in their awareness and approach to palliative care. However, it is important to recognise that policy is also developed at a local level and may be informed by guidance issued by the Irish Association of Palliative Care or the European Association of Palliative Care.

4.2.5 The Irish Association of Palliative Care

The Irish Association of Palliative Care (IAPC) was established in 1993.¹⁵² Members of the IAPC include professionals involved in all aspects of palliative care

149 Ibid. 33.

150 Ibid. 32–33. In 14% of cases the patient would have benefited from specialist palliative care but did not receive it.

151 Ibid. 33.

152 Irish Association of Palliative Care, 'About Us' < <http://www.iapc.ie/about-us/> > accessed 16 November 2017.

including doctors, nurses, psychologists, physiotherapists, and dieticians. IAPC seek to promote palliative care in Ireland and internationally through education, publications, and engagement with national bodies. The drafting of guidelines on palliative care practices is not a responsibility or an aim of the IAPC but it has developed resources in this area. As much of the legal framework is reliant on policy developed at the local level it is likely that the reports and guidance issued by bodies such as the IAPC will have an influence on healthcare professionals providing specialist palliative care. In this respect, the IAPC has published a discussion paper on palliative sedation¹⁵³ and a position paper on artificial hydration¹⁵⁴ which will be discussed in this section.

Discussion paper on palliative sedation

The IAPC discussion paper on palliative sedation was published in March 2011, and functioned to encourage wider discussion and feedback on this practice. The discussion paper is also to act as a ‘focus point’ when aspects of palliative sedation are considered. The discussion paper addresses the decision-making process for commencing palliative sedation, the decision to withhold or withdraw artificial nutrition and hydration, and it provides an explanation of refractory symptoms. In relation to the latter point, guidance can greatly assist the medical practitioner in identifying appropriate steps to be taken in the care of the patient. A refractory symptom is defined in the discussion paper as, ‘symptoms that are uncontrolled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness’.¹⁵⁵ In order to determine whether a symptom is refractory, the IAPC quoted Rousseau who suggests that:

the clinician must perceive that further invasive or non invasive interventions are either incapable of providing adequate relief, or that the therapy is associated with excessive and intolerable acute or chronic morbidity and is unlikely to provide relief within a tolerable time frame.¹⁵⁶

The paper identifies common physical symptoms which give rise to palliative sedation but there is no defined timeframe in which sedation is considered appropriate. In contrast to this, the paper appears to suggest that sedation for psychological symptoms such as existential or emotional distress may be permitted when the prognosis is limited to hours or days.

153 Irish Association of Palliative Care, ‘Palliative Sedation’ (March 2011).

154 Irish Association of Palliative Care, ‘Artificial Hydration in Terminally Ill Patients’ (March 2011).

155 N.I. Cherny and R.K. Portenoy, ‘Sedation in the management of refractory symptoms: guidelines for evaluation and treatment’ (1994) 10 *Journal of Palliative Care* 31 quoted in IAPC (note 153) 2.

156 P. Rousseau, ‘The ethical validity and clinical experience of palliative sedation’ (2000) 75(10) *Mayo Clinic Proceedings* 1064 quoted in IAPC (note 153) 2.

The decision-making process provided for in the discussion paper is to be informed by members of the multi-disciplinary care team and reference should be made to the following:

- the patient's general condition, including the cause of the intolerable distress, treatments that have been attempted, limitations of other options of care
- the rationale for the decision that palliative sedation is the only method available for achieving symptom relief within an acceptable time frame (i.e., the symptoms are truly refractory)
- the aims of sedation
- the method of sedation
- the anticipated effects of sedation, including degree of reduction in consciousness levels, communication and oral intake
- the potential uncommon risks such as paradoxical agitation, delayed or inadequate relief
- medical treatments and nursing care to be maintained during sedation: treatments and care to maximize the patient's comfort are continued
- the expected outcomes if palliative sedation is not performed, including other treatment options, degree of suffering likely to persist with each option and expected survival with each option
- commitment to the patient's well being and provision of best possible care¹⁵⁷

These are steps which medical practitioners may already take but by setting them out in such a manner it provides clarity to all people involved in the care of the patient and reduces any ad hoc image of decision-making in palliative care.

The IAPC paper provided brief guidance for decisions about hydration and nutrition and underlined the distinction between these practices. Each decision requires an assessment of the benefits and burdens which would result for the patient. Overall, the discussion paper provides more detailed guidance than the IMC. Yet, the status of the discussion paper means it lacks enforceability and there is no guarantee that it informs specialist palliative care decisions in practice. A relatively minor point is the reference to the doctrine of double effect included in the document. The doctrine was considered in Chapter 2 where it was argued that it is inappropriate for palliative sedation to be guided by an ethical justification. Reference to the doctrine may be seen to somewhat undercut the value of the guidance set out in the IAPC paper.

Position paper on artificial hydration in terminally ill patients

The IAPC position paper on artificial hydration was also published in March 2011 and it examines ethical issues arising from artificial hydration in terminally ill patients. The law relating to treatment withdrawal is set out and the paper highlights the importance of acting in the best interests of the patient. On this point, it

¹⁵⁷ IAPC (note 153) 3.

notes that '[g]ood clinical care does not involve the use of treatments that are excessively burdensome or futile.'¹⁵⁸ It follows that an assessment of benefits and burdens is to focus on the treatment and not the patient's life. Appropriate care requires this assessment to be regularly carried out in order to respond to changes in the patient's condition. However, the paper illustrates the uncertainty between the provision of hydration and ensuring patient comfort. Reference was made to a Cochrane Review on artificial hydration as well as the review conducted by Raijmakers et al., both of which were discussed in Chapter 2 and which highlighted the lack of a definitive position. Accordingly, the position paper states that 'the use of artificial hydration in terminally ill patients is more likely to be governed by established practice and culture, physician bias and place of care, rather than by any systematic, objective assessment of appropriateness'.¹⁵⁹ Such uncertainty and potential for inconsistent care is unwelcome but not wholly surprising in the absence of clear national guidelines. Despite this, the IAPC paper does set out some guidance on the decision-making process.

Decisions are to be based on the patient's individual circumstances and policies of always or never providing artificial hydration are described as 'ethically indefensible'.¹⁶⁰ The decision is to be informed by consultation with members of the multidisciplinary care team as well as the patient's family. Difficult clinical situations, may require engagement with a local clinical ethics committee or with a specialist in the management of terminally ill patients. Discussion of sedation is largely absent in this position paper. This omission is somewhat surprising as the order in which these decisions are made will impact on the potential for the patient to be involved in further treatment decisions.

4.3 The European Association of Palliative Care

The European Association of Palliative Care (EAPC) was established in 1988 and aims to promote palliative care in Europe through information, education, and research. The work of the EAPC is often disseminated through publications which require initiatives at a national level to ensure they are implemented. As such, the recommendations of the EAPC are not directly enforceable in the UK and Ireland but may be drawn on in the development of local policy. The IAPC, Association of Palliative Medicine of Great Britain and Ireland, and Hospice UK are members of the EAPC; as are over 50 other associations across 34 countries.¹⁶¹ EAPC publications have examined many different aspects of palliative care.¹⁶²

158 IAPC (note 154) 1.

159 Ibid. 2.

160 Ibid.

161 European Association of Palliative Care, 'EAPC Membership and Benefits' <<http://www.eapcnet.eu/Themes/Membership.aspx>> accessed 15 November 2017.

162 G.W. Hanks and others, 'Morphine and alternative opioids in cancer pain: the EAPC recommendations' (2001) 84(5) *British Journal of Cancer* 587; F. Stiefel, 'Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association of Palliative Care' (2001) 9(7) *Supportive Care in Cancer* 477; N. Cherny

However, this section will concentrate on the EAPC recommended framework for the use of sedation in palliative care.¹⁶³

4.3.1 EAPC recommended framework for the use of sedation in palliative care

The EAPC recommended framework for the use of sedation was published in 2009. The importance of procedural guidelines and the consequences of poor practice were clearly recognised in this publication. For instance, '[i]nattention to potential risks and problematic practices can lead to harmful and unethical practice which may undermine the credibility and reputation of responsible clinicians and institutions as well as the discipline of palliative medicine more generally.'¹⁶⁴ Guidelines were described in this framework as being useful in 'educating medical providers, setting procedural standards for good clinical practice, promoting optimal care and conveying the important message to staff, patients and families that palliative sedation is an accepted, ethical practice when used in appropriate situations.'¹⁶⁵ The framework is not automatically incorporated in the national system of EAPC members but requires additional steps to be taken for its adoption. The framework could be adopted in its original form or may be modified to best reflect national cultures, norms, or legal considerations. However, research by Abarshi and Payne suggests that few countries have since adopted the framework.¹⁶⁶

The recommended framework for the use of sedation in palliative care set out a ten-item framework that addresses fundamental clinical issues. It includes discussion with the patient and maintenance of appropriate documentation. Of particular relevance, are the indications for sedation, the selection of the sedation method, and guidance on nutrition and hydration.

The relevant indication for sedation is described in the framework as 'intolerable distress due to physical symptoms, when there is a lack of other methods for palliation within an acceptable time frame and without unacceptable adverse effects (refractoriness)'.¹⁶⁷ It suggests that continuous deep sedation should only be administered when the prognosis is that of hours or days at most. Juth et al. argue that the EAPC framework should have adopted a clearer approach to refractory

and others, 'Strategies to manage the adverse effects of oral morphine: an evidence-based report' (2001) 19(9) *Journal of Clinical Oncology* 25; A. Caraceni and others, 'Pain measurement tools and methods in clinical research in palliative care: recommendations of an Expert Working Group of the European Association of Palliative Care' (2002) 23(3) *Journal of Pain and Symptom Management* 239.

163 N.I. Cherny, L. Radbruch and The Board of the European Association for Palliative Care, 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care' (2009) 23(7) *Palliative Medicine* 581.

164 Ibid.

165 Ibid. 583.

166 E. Abarshi and S. Payne, 'Awareness of the EAPC recommendations on palliative sedation: a web-based survey' (2014) 21(2) *European Journal of Palliative Care* 81, 85 'The vast majority (92%) either said that their country had not adopted the framework or did not know whether this was the case or not.'

167 Cherny (note 163) 584.

suffering.¹⁶⁸ This is based on the suggestion that it is not clear what symptoms are necessary for the administration of sedation, and there is ambiguity as to whether the patient or the healthcare professional is the primary party to make the determination. The issue is placed in further relief by the possibility of non-physical symptoms. The framework goes so far as to include an appendix detailing special considerations for refractory existential or psychological distress. Again, Juth et al. suggest that the framework lacks ‘a more thorough analysis of intolerable suffering, refractory symptoms and the relation between them’.¹⁶⁹ In any case, it would appear that continuous sedation is condoned for non-physical symptoms provided appropriate evaluation takes place, the patient is in the advanced stages of a terminal illness, and repeated trials of respite sedation have been performed.

As noted above, the framework provides guidance on the selection of an appropriate level of sedation and associated practices. The general guidance on the provision of sedation is that it should be the lowest necessary to provide appropriate relief from suffering.¹⁷⁰ On this point, the titration of sedative drugs is set out as well as setting out the approach to beginning assessment, and continuing assessment of the patient’s pain management needs. A stepped approach to sedation is advised whereby deeper sedation should be administered when a mild level of sedation has not been effective, although continuous deep sedation could be selected first in certain limited circumstances.¹⁷¹ In relation to nutrition and hydration, the framework underlines the independence of the decisions on sedation and the provision of artificial nutrition and hydration but refrains from setting a definitive position on treatment withdrawal. Instead, the EAPC suggest that this is a decision for the patient while also weighing up the ‘estimated benefits/harms in light of the treatment aim’.¹⁷²

The EAPC framework highlights the potential problems raised by palliative sedation. It not only acknowledges potential problems for the patient such as ‘hastening death’¹⁷³ but also recognises distress which families may experience as a result of sedation. The potential for abuse of sedation has been recognised within the framework. Such abuse may not only be an excessive provision of sedation but may also be exhibited by an insufficient level of sedation given to a patient. By educating all parties involved and clarifying the role of palliative sedation this framework can improve the practice of palliative sedation and allow for palliative care to be provided in a much clearer manner. This serves to improve consistency and allows the patient greater understanding and input to their care. Nevertheless,

168 N. Juth and others, ‘European Association for Palliative Care (EAPC) framework for palliative sedation: an ethical discussion’ (2010) 9(20) *BMC Palliative Care*.

169 Ibid. 3.

170 Cherny (note 163) 586.

171 Ibid. ‘Continuous deep sedation could be selected first if: (1) the suffering is intense; (2) the suffering is definitely refractory; (3) death is anticipated within hours or a few days; (4) the patient’s wish is explicit; and (5) in the setting of an end-of-life catastrophic event such as massive haemorrhage or asphyxia.

172 Ibid. 587.

173 Ibid. 582.

this is guidance which presently can only prove effective if implemented by local policy. Awareness of this framework is not flawless among EAPC members and this raises more substantial questions about the wider knowledge and perception of the guidance. The 2012 survey conducted by Abarshi and Payne demonstrated that around '70% of individual members and 80% of collective members were aware of the EAPC framework on palliative sedation'.¹⁷⁴ Greatest awareness was among researchers (83%), followed by physicians (78%), and nurses (67%).¹⁷⁵ It follows that knowledge of the framework among non-EAPC members would be expected to be considerably lower. Yet, healthcare professionals must be aware of these issues if patients are to be provided with the right care at the right time and in the right location.

4.4 Palliative care as a legal process

David Rothman previously commented, 'that dying has become a legal process is not an unqualified sign of progress'.¹⁷⁶ It is difficult to escape the point that palliative and specialist palliative care raise numerous legal and ethical concerns. These concerns have emerged in tandem with developments in palliative care. Care has become more formalised and defined to the point where palliative medicine has specialty status in several jurisdictions. Increased research and analysis has subsequently placed legal challenges in sharper relief. The law is often slow to respond to change but it is inevitable that more formal legal structures will be put in place for palliative care at some point in the future.

While the law may move at a slower pace its impact can be substantial. As noted above, there have been multiple attempts to enact legislation in England which would alter the planning for palliative care services and require greater steps to be taken by healthcare professionals. In other jurisdictions the response has been tied to debates around euthanasia. Palliative care organisations in Ireland and the UK are therefore relatively well-placed to define a role for the law without needing to appease parties seeking a liberalisation of the law on euthanasia or looking to subvert specialist palliative care practices. There is the opportunity to shape the law in a way which avoids a legalistic or box ticking response to which the LCP succumbed. It is suggested that the legal framework provides an avenue for the continued promotion and advancement of palliative care. This work will turn to consider the legal framework in the Netherlands along with France over the next two chapters. Turning to consider these jurisdictions will involve examining how they have attempted to define the legal status of specialist palliative care practices. It will show how guidelines can be tailored and updated to respond to practical challenges. Moreover, the potential of legislation to navigate the distinctions at the

174 Abarshi (note 166) 83.

175 Ibid.

176 D.J. Rothman, *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (Aldine Transaction 1991) 261.

end of life will be considered. All of which serves to further illustrate the complexity and influence of debates on the borders of medical practice.

4.5 Conclusion

This chapter outlined and examined elements of the legal framework not addressed in preceding chapters. In addition, it drew out the recurring themes in palliative care strategies and planning documents. The failings and weaknesses in palliative care have proven to be resilient over the years. As Prof Higginson noted in relation to the ‘Dying without dignity’ report, ‘it does not tell us what we did not know already. ... But the issue now is to respond to the report and take some action and change things.’¹⁷⁷ Continuing to apply the same approach will not lead to the necessary improvements. The necessary action may involve training, education, greater clarity on pain and symptom management, or increased commissioning of palliative resources. It is important to reflect on the role of the legal framework in facilitating change in these areas. The law undoubtedly inhabits an important role in palliative care as already demonstrated through discussion of human rights and criminal law. However, as was noted at the outset of this chapter it has often been an overlooked element in palliative care provision and it is necessary to explore the potential it offers in shaping palliative care for healthcare professionals and the patient.

¹⁷⁷ House of Commons Public Administration and Constitutional Affairs Committee (note 19) 7.

5 The legal framework for palliative care in the Netherlands

5.0 Introduction

Professional guidelines serve a crucial role in defining the standards which healthcare professionals must adhere to as well as defining the boundaries of medical practice. Quite often professional guidelines navigate a maze of clinical, ethical, and legal matters while attempting to provide clarity to the healthcare professional and, by extension, the patient. Professional guidelines can therefore serve to circumscribe what constitutes normal medical practice. Consequently, professional guidelines have had an important role in jurisdictions such as the Netherlands. This jurisdiction has established detailed professional guidelines for the provision of palliative sedation rather than pursuing a legislative approach. The introduction of the guidelines was heavily influenced by the need to distinguish specialist palliative care practices from euthanasia. The approach employed to achieve this was to define palliative sedation as normal medical practice. In examining the Dutch system of palliative care it is important to recognise that the model of regulation cannot be wholly separated from the structure of Dutch society, the broader legal framework for end of life practices, cultural factors, and the system of healthcare in the Netherlands.¹ Nonetheless, as more jurisdictions move towards the legalisation of forms of physician aided dying it is necessary to consider how the distinction between practices can be maintained so palliative care is not subsumed or compromised by the debates on or practice of voluntary active euthanasia and physician assisted suicide.

This chapter will first outline the development of palliative care in the Netherlands. This gives an image of the Dutch healthcare system and illustrates why this jurisdiction serves as a useful comparator. Second, the guidelines on palliative sedation published by the Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association) (KNMG) will be examined. The background to these guidelines will be set out before moving on to outline the main provisions and consider their impact on end-of-life care in the Netherlands. A key consideration for this discussion is whether the KNMG Guideline is

1 S. Gevers, 'Euthanasia: law and practice in The Netherlands' (1996) 52(2) *British Medical Bulletin* 326, 333.

successful in framing palliative sedation as normal medical practice and can therefore serve as a justification. It will be argued that, for the most part, the guideline is effective in defining palliative sedation as normal medical practice but there are aspects of the Guideline which serve to obfuscate and avoid fully engaging with contentious aspects of the practice. This may often be linked back to the insistence on the normal nature of sedation. Additional concerns for this chapter include how the guidelines protect and promote the human rights of the patient, and whether it provides sufficient clarity and certainty for both the patient and the healthcare professional.

5.1 The development of palliative care in the Netherlands

Palliative care in the Netherlands has had a similar development trajectory to palliative care in the United Kingdom and Ireland. These jurisdictions also share a common understanding of what palliative care involves and how it is to be defined. For instance, the Dutch government policy paper titled 'Palliative Care for Terminally Ill Patients in the Netherlands'² cites the World Health Organization definition of palliative care.³ This is the same definition which has been used by UK and Irish reports on palliative care.⁴ In addition, both the Netherlands and the UK and Ireland began to develop palliative care services around the same time.

In 1975 the Antonius-IJsselmonde nursing home began to focus on the provision of palliative care in an attempt to enhance the type of care available to the dying patient.⁵ This was the first healthcare provider in the Netherlands to adopt this type of focused approach to end-of-life care. Aspects of care which the Antonius-IJsselmonde nursing home focused on developing included specialist nursing care, bereavement support, and spiritual care.⁶ The time after 1975 signalled a considerable change in how end-of-life care was viewed and provided in the Netherlands. For example, Gronemeyer et al. suggested that '[a]fter 1975, death and dying were decreasingly considered a taboo period and society started to acknowledge its duty to care for terminally ill people.'⁷ In a similar vein, the developments after 1975 were described by Biesenbeek as 'a period of reversal; a period in which the

2 A.L. Francke, 'Palliative Care for Terminally Ill Patients in the Netherlands: Dutch Government Policy' (The Hague 2003).

3 C. Sepúlveda and others, 'Palliative care: the World Health Organization's global perspective' (2002) 24(2) *Journal of Pain and Symptom Management* 91, 94; R.J.P.A. Janssens and H. ten Have, 'The concept of palliative care in the Netherlands' (2001) 15 *Palliative Medicine* 481, 482 'Most definitions of palliative care in the Netherlands are based on that developed by the World Health Organization in 1990.'; Netherlands Programme for Palliative Care, 'NPTN: palliative care comes under the spotlight in the Netherlands' (2009) 16(3) *European Journal of Palliative Care* 15.

4 Health Service Executive, 'Palliative Care Services – Five Year/Medium Term Development Framework' (Health Service Executive 2009).

5 R. Gronemeyer and others, *Helping People at the End of their Lives: Hospice and Palliative Care in Europe* (Lit Verlag 2005) 231.

6 Janssens (note 3) 482.

7 Gronemeyer (note 5) 231.

dying process had been brought more into the open and in which society had started to acknowledge its duty to care for the terminally ill.⁸ As such, a number of healthcare providers in the Netherlands began to focus on the development of palliative care practices from this time.

A significant point in the development of palliative care in the Netherlands was the establishment of a number of hospices in the early 1990s. The Johannes hospice in Vleuten was founded in 1991,⁹ the Kuria hospice in Amsterdam was set up in 1992, and the Rozenheuvel hospice was established in 1994.¹⁰ It has been suggested that by setting up these hospices, people were attempting to 'make a concrete statement in the euthanasia discussion as a counterbalance to the euthanasia movement'.¹¹ This indicates a demarcation between the provision of palliative care and euthanasia. Additionally, the impact of hospice care in the Netherlands can be illustrated by the experience of Rozenheuvel hospice. 571 patients were admitted to Rozenheuvel in the four years after it opened.¹² A quarter of these patients had made a request for euthanasia should the pain become unbearable.¹³ However, there were only two people from the 571 patients who went through with their request for euthanasia.¹⁴ One interpretation of this is that palliative care can provide appropriate pain management along with other support necessary for the care of the patient. However, these figures could also be interpreted in a manner which suggests that specialist palliative care practices function similarly to euthanasia and therefore requests for euthanasia were needless in the circumstances. These conflicting interpretations illustrate the enduring tension between these practices. In any case, hospice care continued to develop in the Netherlands. There were 86 inpatient hospice facilities in 2007 and this rose to 212 inpatient hospice facilities by 2013.¹⁵ These figures include individual hospice facilities as well as palliative care units in tertiary and non-tertiary healthcare institutions. The expansion in the

8 Janssens (note 3) 482.

9 B. Gordijn and R. Janssens, 'Euthanasia and palliative care in the Netherlands: an analysis of the latest developments' (2004) 12(3) *Health Care Analysis* 195, 199.

10 Ibid; R.J.P.A. Janssens and others, 'Hospice and euthanasia in the Netherlands: an ethical point of view' (1999) 25(5) *Journal of Medical Ethics* 408, 409 It is the Rozenheuvel hospice which can be said to best reflect the English St Christopher's Hospice model for palliative care.

11 Gronemeyer (note 5) 231; A. Brinkman and J. Gootjes, 'NPTN: palliative care comes under the spotlight in the Netherlands' (2009) 16(3) *European Journal of Palliative Care* 151, 151 'The debate about the practice of euthanasia also played an important role. For the Dutch hospice pioneers, the most important motivation was to provide better care for the dying.'

12 Gordijn (note 9) 202.

13 Ibid.

14 Ibid.

15 E. West and others, 'Hospice care in the Netherlands: who applies and who is admitted to inpatient care?' (2016) 16 *BMC Health Services Research* 33; C. Centeno and others, 'EAPC Atlas of Palliative Care in Europe' (IAHPC Press 2007); C. Centeno and others, 'EAPC Atlas of Palliative Care 2013' (EAPC Press 2013); See also Brinkman (note 11) 151.

provision of palliative care was accompanied by an increased government focus on this form of care from 1996 onwards.¹⁶

A policy statement issued by the Dutch government in 1996 highlighted the importance of further developing palliative care in the Netherlands.¹⁷ This increased focus was wound up with a number of other motivations. In particular, several members of the Dutch Parliament suggested that a rise in the number of hospices was likely to reduce the prevalence of euthanasia.¹⁸ This point is illustrated in a letter to the Dutch Parliament in which the Minister for Health set out that:

It is certainly so that at times, in the context of extremely severe suffering, good palliative care, adequate pain treatment and a familiar surrounding can shift the borders for the request to have euthanasia carried out and can at times even prevent the request.¹⁹

This quote suggests that palliative care was viewed more favourably than euthanasia and was regarded as a more ethically acceptable practice. In this letter, the Minister for Health also set out that a small amount of funding was to be made available for the development of palliative care.²⁰ The purpose of this funding was to develop palliative care provision in existing services such as nursing homes, hospitals, and as part of home care services.²¹ The reason for adopting this approach was a view that there was already a high standard of regular health care in the Netherlands.²² On that basis there was no perceived need for an independent palliative care provider.²³ This funding led to a number of initiatives aimed at promoting palliative care.²⁴ These initiatives promoted research and strengthened cooperation among palliative care providers.

Palliative care in the Netherlands is provided in nursing homes,²⁵ care homes,²⁶ independent and volunteer run hospices, and hospitals,²⁷ and in the patient's

16 Gordijn (note 9) 199; Gordijn and Janssens suggested that it was the visit of the Dutch Queen and the Minister for Health to Rozenheuvel which 'instigated Members of Parliament to raise questions regarding the organization of palliative care in the Netherlands'.

17 Gronemeyer (note 5) 231.

18 Ibid. 232; Janssens (note 3) 483.

19 Gordijn (note 9) 201.

20 Gordijn (note 9) 199 Minister of Health 'promised to further develop palliative care making available 250,000 guilders (\$120,000).'

21 Ibid.

22 Ibid.

23 Ibid.

24 Ibid. Six centres for the development of palliative care (COPZ's) were established with the purpose of improving 'coordination in care giving, develop educational modules and increase expertise and carry out research activities'; Netherlands Programme for Palliative Care (note 3); Francke (note 2) 19.

25 Brinkman (note 11) 151 '[u]ntil the 1980s, most people with severe illness were treated in hospitals and nursing homes.'; Gronemeyer (note 5) 237.

26 Francke (note 2) 9.

27 Francke (note 2) 11 Palliative care in a hospital is often provided as part of 'regional palliative care networks.' As such, hospitals are part of the broader system of palliative

home. In 2006, the final place of care for patients suffering from cancer or other chronic diseases in the Netherlands was the home (31%),²⁸ hospital (28%),²⁹ nursing home (25%),³⁰ and care home (11%).³¹ 5% of patients died in another type of healthcare facility including independent hospices.³² The percentage of patients dying in a palliative care unit subsequently rose to 10.4%.³³ The broad range of palliative care providers underlines the importance of high quality palliative care as part of the general healthcare system. Such an approach moves palliative care from the margins to a more central position in the care of a patient. In these locations, the doctor has an essential role in ensuring the patient is provided with appropriate palliative care.³⁴ As a result, the legal framework for specialist palliative care in the Netherlands chiefly concentrates on the general practitioner although reference is made to other professions which are closely involved in providing patient care. This approach is evidenced in the guidelines published by the Royal Dutch Medical Association (KNMG).

5.2 Guidelines on specialist palliative care in the Netherlands

The manner in which palliative sedation was regulated in the Netherlands received particular attention in light of comments made by the Dutch Attorney General, Joan de Wijkerslooth, in 2003. It was suggested by de Wijkerslooth that ‘if sedation goes hand in hand with a decision to withhold hydration, it would amount to euthanasia albeit in a slow manner’.³⁵ This led de Wijkerslooth to call for palliative

care in the Netherlands but do not tend to provide comprehensive palliative care facilities. While a number of nursing homes contained a hospice unit this rarely occurs in the hospital setting.

28 L.F.J. van der Velden and others, ‘Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data’ (2009) 8 *BMC Palliative Care* 4.

29 Ibid.

30 Ibid.

31 Ibid.

32 Ibid. ‘In 5% the place of death was either another place than those mentioned before or unknown. It may be assumed that “other” includes, for instance, non-acute deaths in institutions for the mentally handicapped, mental healthcare institutions or one the 230 independent hospices that exists nowadays in the Netherlands. Ten years ago, the number of independent hospices was only some 40.’

33 L. van den Block and others, ‘Transitions between health care settings in the final three months of life in four EU countries’ (2015) 25(4) *European Journal of Public Health* 569, 571.

34 Francke (note 2) 6 Research conducted by Francke demonstrated that the general practitioner ‘has contact a total of 26 times with a cancer patient in the palliative phase’ and this contact is normally initiated by the doctor.

35 Gordijn (note 9) 204 Research by Van der Wal et al. suggested that terminal sedation was administered in ‘6% of all deaths in the Netherlands (8,500 times a year)’. Additionally, hydration was not provided in two thirds of such cases; G. Van der Wal and others, ‘Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie’ (Utrecht, 2003).

sedation to be governed by the same legal controls as euthanasia.³⁶ In such a scenario, the regional commission for overseeing voluntary active euthanasia and physician assisted suicide would be notified in circumstances where a patient is continuously sedated and hydration is withdrawn.³⁷ Such an approach would place specialist palliative care in the realm of euthanasia.

The impetus for the Attorney General's suggestion was a Dutch study on end-of-life care which indicated that palliative sedation had been administered in 4–10% of all deaths in the Netherlands.³⁸ However, these statistics do not suggest that sedation ultimately caused the death of the patient. Nevertheless, it is understandable that the Attorney General began to question the categorisation of palliative sedation and its relationship to euthanasia based on these figures.

The potential re-categorisation of palliative sedation was criticised by providers of palliative care who were of the opinion that if specialist palliative practices are carried out correctly then it is a type of pain and symptom control, 'a form of normal medical treatment about which doctors and patients decide'.³⁹ The Dutch Health Minister at the time viewed palliative sedation and the withdrawal of artificial nutrition and hydration as normal medical treatment.⁴⁰ The KNMG described the suggestion of the Attorney General as a 'frightening prospect'.⁴¹ Overall, the Attorney General's suggestion was not supported by the Dutch government and they instead believed it necessary to introduce a national guideline for palliative sedation.⁴² This was also an attempt to mitigate the need to introduce legislation on specialist palliative care practices. A range of professional guidelines were introduced around this time which sought to emphasise the point that specialist palliative care practices are a normal aspect of medical treatment.⁴³ The professional guidelines appear to have been successful as, at the time of writing, there has been no legislation enacted in the Netherlands which is aimed specifically at specialist palliative care practices.

This chapter will predominantly concentrate on the guidelines issued by the KNMG in 2005 and the revised guidelines published in 2009 as these guidelines

36 T. Sheldon, "Terminal sedation" different from euthanasia, Dutch ministers agree' (2003) 327(7413) *British Medical Journal* 465, 465.

37 Gordijn (note 9) 204–205 'In his view, all cases of terminal sedation where hydration was withheld would need to be reported to the regional commission for euthanasia and PAS.'

38 Sheldon (note 37) 465; J. Legemaate, 'The Dutch national guideline on palliative sedation' in S. Sterckx and others, *Continuous Sedation at the End of Life: Ethical, Clinical, and Legal Perspectives* (Cambridge University Press 2013) 149.

39 Gordijn (note 9) 205.

40 Sheldon (note 37) 465.

41 Ibid.

42 M. Verkerk and others, 'A national guideline for palliative sedation in The Netherlands' (2007) 34(6) *Journal of Pain and Symptom Management* 666, 666–667.

43 R. Janssens and others, 'Palliative sedation: not just normal medical practice. Ethical reflections on the Royal Dutch Medical Association's guideline on palliative sedation' (2012) 38 *Journal of Medical Ethics* 664, 664 'The main premise of the Royal Dutch Medical Association's (RDMA) guideline on palliative sedation is that palliative sedation, contrary to euthanasia, is normal medical practice.'

are closely linked to the physician's professional standards in the Netherlands. Additionally, subsequent guidelines such as those drafted by the Integraal Kankercentrum Nederland (Comprehensive Cancer Centers of the Netherlands) were aligned with the KNMG guideline on palliative sedation. Further refinements were in line with updated guidelines issued by the KNMG. As it is the guidance of the KNMG which appears to be a cornerstone for the provision of palliative sedation it is important to examine the contents and impact of this guideline in detail.

5.3 The KNMG Guideline for Palliative Sedation

The KNMG is the professional body for doctors in the Netherlands.⁴⁴ Activities of the KNMG include the development of guidelines and policies for doctors, and overseeing the training and registration of specialists. The Guideline for Palliative Sedation was developed by a committee appointed by the KNMG. This allowed for a broad range of input as the committee included a professor in the ethics of care, two oncologists, two nursing home physicians, an anaesthesiologist, two general practitioners, a medical law coordinator, and a policy advisor.⁴⁵ The Guideline which the KNMG committee developed is now an element of the physician's professional standards which a physician is obliged to follow.⁴⁶ The need to distinguish specialist palliative care from euthanasia was understood by the committee developing the Guideline.⁴⁷ In line with this, the approach taken was to assert that palliative sedation was a normal component of medical practice. This is established and affirmed in the Guideline through sections on the prognosis of the terminally ill patient, the intention of the physician, and consultation with an expert physician.⁴⁸ The first edition of the Guideline for Palliative Sedation was published in 2005⁴⁹ and since that time the KNMG has actively monitored the Guideline. There was criticism of certain aspects of the Guideline for Palliative Sedation which led to the KNMG attempting to resolve these issues by publishing revised guidance in 2009. The Guideline will be examined on a chapter by chapter basis with a focus on how palliative sedation is defined as normal medical practice.

44 'The Royal Dutch Medical Association' <<http://knmg.artsennet.nl/Over-KNMG/About-KNMG.htm>> accessed 20 August 2017.

45 Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2009) 64.

46 Verkerk (note 42) 667.

47 Janssens (note 43) 664.

48 Ibid. 'This message is founded on stipulating the following two conditions: the prognosis of the patient should be less than 2 weeks, and the aim of the physician should be to relieve suffering and not to shorten the patient's life. A third element follows from these conditions: if palliative sedation does not shorten life, expert consultation, mandatory as it is in euthanasia cases, is just optional in palliative sedation cases.'

49 Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2005).

5.3.1 Defining the practice of palliative sedation

Chapter 2 of the revised Guideline defines palliative sedation and explains that it is ‘administered as part of an overall plan or process of palliative care’.⁵⁰ The definition of palliative sedation in the Guideline is careful to distinguish normative elements of the practice and thereby establish a definition which is as precise as possible. The committee define palliative sedation as ‘[t]he deliberate lowering of a patient’s level of consciousness in the last stages of life.’⁵¹ Three elements of the definition are discussed in slightly more detail, namely the lowering of consciousness, the deliberate nature of sedation, and the patient’s prognosis. The Guideline stipulates that it is the level of symptom control rather than a designated reduction in consciousness which determines the combination, level, and duration of the sedative drugs administered. Furthermore, the evaluation and decision-making processes must concentrate on alleviating the patient’s suffering in order to establish a calm and tolerable situation.⁵² As noted in chapter 1, palliative sedation may be provided at different levels depending on the patient’s condition. The Guideline reflects this as the term ‘palliative sedation’ is used to refer to both continuous sedation and intermittent sedation. A majority of the Guideline concentrates on continuous sedation while intermittent sedation is mainly discussed in chapter 8.

Chapter 2 also set out empirical data on the provision of palliative sedation in the Netherlands which ranged from the main symptoms leading to palliative care,⁵³ to the frequency with which artificial nutrition and hydration is withdrawn.⁵⁴ These figures created an image of the palliative care culture in the Netherlands and served to set up discussion of the substantive guidelines on issues such as the indications and preconditions for palliative sedation.

5.3.2 Indications and preconditions for palliative sedation

The third chapter of the KNMG Guideline for Palliative Sedation addresses the ‘Indications and preconditions for palliative sedation’.⁵⁵ A prime indication is that the patient is experiencing one or more refractory symptoms.⁵⁶ A symptom can be considered refractory if ‘[n]one of the conventional modes of treatment is effective or fast-acting enough, and/or if these modes of treatment are accompanied by

50 Royal Dutch Medical Association (note 45) 17.

51 Ibid. 18.

52 Ibid. 19.

53 Ibid. 20 ‘The symptoms most commonly experienced by patients in the last stages or final week of life are fatigue (83%), dyspnoea (50%), pain (48%), confusion (36%), anxiety (31%), depression (28%) and nausea and vomiting (25%). Fatigue is perceived as the greatest burden, followed by pain, anxiety, dyspnoea, depression, nausea/vomiting and confusion, in that order’.

54 Ibid. 21 ‘Continuous, deep sedation was administered together with the non-administration of food or fluids in 5.4% of all deaths.’

55 Ibid. 22.

56 Ibid.

unacceptable side-effects.⁵⁷ There is a considerable subjective element in diagnosing a refractory symptom. For example, what constitutes an unacceptable side effect is likely to change depending on the individual patient. Accordingly, the Guideline recognises the importance of a patient's involvement in decisions on palliative care and suggests that '[i]t often will be appropriate for the physician and patient to decide together whether or not, on balance, a symptom is refractory.'⁵⁸ The decision as to whether a symptom is untreatable, and therefore refractory, is based largely on two factors, namely the likely effectiveness of the treatment, and the discomfort or other side-effects related to the treatment.

The Guideline sets out symptoms which commonly require palliative sedation but it must be shown 'beyond reasonable doubt'⁵⁹ that the symptoms are untreatable. In order to demonstrate this, it is necessary that any reversible cause of suffering is assessed and appropriately distinguished prior to a decision on the administration of palliative sedation being made.⁶⁰ This is to include non-somatic causes of suffering and may include anxiety and causes of agitation. Again, the Guideline highlights the necessity of considering the patient's feelings about issues including the discomfort of additional diagnostic tests. The decision to label a symptom as refractory leaves a considerable degree of discretion to the doctor and patient but at the same time the guidance is not so broad as to be meaningless. For example, the Guideline includes a 'flow diagram' to assist in the identification of refractory symptoms.⁶¹ This provides a clear reference for both the doctor and the patient as to whether a symptom is likely to be refractory and promotes a degree of certainty in the provision of palliative sedation. Accordingly, a person who has a life-threatening condition but does not exhibit a refractory symptom cannot choose palliative sedation. In addition to this, chapter 3 of the Guideline also highlights symptoms which raise difficult ethical and legal issues, namely sedation in the case of existential suffering.

Palliative sedation for existential suffering

A challenging symptom for the Guideline for Palliative Sedation has been the provision of palliative sedation for existential or psychological suffering.⁶² It is possible that this is among the refractory symptoms which result in unbearable suffering.⁶³ Nonetheless, the identification of existential suffering is such that it

57 Ibid.

58 Ibid.

59 Ibid. 23.

60 Ibid. 'reversible causes of suffering must be meticulously excluded before a decision is taken to administer palliative sedation.'

61 Ibid. 25.

62 Non-somatic suffering has also raised challenging issues for euthanasia. Text to note 26 and note 31 in chapter 2.

63 Royal Dutch Medical Association (note 45) 24. 'Existential suffering may be expressed as feelings of pointlessness, emptiness, existential distress, a desire not to experience death or the dying process consciously, psychosocial problems, spiritual problems, or for instance the desire to preserve one's dignity.'

also requires ‘expertise in the areas of psycho-social and spiritual problems’.⁶⁴ The 2005 Guideline was criticised for not allowing palliative sedation for this type of suffering. This point was clarified by the 2009 Guideline which set out that if the patient was also experiencing refractory symptoms then sedation could be administered.⁶⁵ However, existential suffering alone does not justify the provision of palliative sedation. The manner in which existential distress is treated is an important facet in distinguishing specialist palliative care practices from euthanasia. For example, it was highlighted in chapter 1 that sedation for existential distress, in the absence of a refractory symptom, furthers suggestions that specialist palliative care is a form of euthanasia in disguise.

Requisite prognosis for palliative sedation

In addition to the presence of one or more refractory symptoms, the patient should be expected to die within a short period of time, one to two weeks.⁶⁶ This two-week period is important in the Guideline as a longer life expectancy may suggest that the patient dies due to dehydration instead of the underlying illness.⁶⁷ In the Netherlands it is common practice to withdraw hydration from the sedated patient. As such, withdrawing hydration from a patient with a longer prognosis blurs the distinction between specialist palliative care and euthanasia. By seeking to exclude and avoid life-shortening effects the guideline takes a further step towards defining palliative sedation as normal medical practice. Although, it can be questioned whether this required prognosis actually has significance in defining palliative sedation as normal medical practice as opposed to extraordinary medical treatment.

Van Delden is critical of the approach taken in the Guideline on Palliative Sedation. In particular, van Delden argues that life expectancy is difficult to determine in many cases and undermines the categorisation of palliative sedation as normal medical practice. Van Delden makes reference to tools such as the Palliative Prognostic Score and the Palliative Prognostic Index which assist in the estimation of life expectancy but notes that ‘even these do not allow one to make subtle differences between one, two and three weeks of life expectancy.’⁶⁸ The difficulty in determining the patient’s life expectancy was recognised in the Guideline for Palliative Sedation and it was suggested that the guiding factor

64 Ibid.

65 Ibid. 25 ‘However, there are patients who have no refractory symptoms but simply want palliative sedation as a way of avoiding consciously experiencing the end of life. The committee does not regard this as an acceptable indication.’ The guidance on existential suffering may reflect the challenging cases which have arisen on euthanasia in the Netherlands.

66 Ibid. 25.

67 Ibid. 26 ‘If the patient’s life expectancy exceeded one to two weeks, the non-administration of fluids would cause dehydration and hasten the time of death.’

68 J.J.M. van Delden, ‘The ethical evaluation of continuous sedation at the end of life’ in S. Sterckx and others, *Continuous Sedation at the End of Life: Ethical, Clinical, and Legal Perspectives* (Cambridge University Press 2013) 221.

should be an observation for certain signs which demonstrate the patient's condition is worsening.⁶⁹ These signs include the patient ceasing to eat and drink, tiredness, drowsiness, and disorientation.⁷⁰ These signs along with the worsening symptoms of illness serve to frame the decision-making process. The Guideline suggests that these are the signs which the healthcare professional is to focus on in identifying whether the patient is dying.⁷¹ As noted in Chapter 1, there are many illnesses for which it is particularly difficult to accurately predict life expectancy.⁷²

In the Guideline it is recognised that there are different disease trajectories and palliative care must adapt for each patient's condition. There may, for instance, be occasions when a refractory symptom is present but death is not expected in the one to two-week period prescribed by the Guideline. This may be seen in conditions such as amyotrophic lateral sclerosis or chronic obstructive pulmonary disease. Patients suffering from these conditions have often been excluded from palliative care services due to the difficulty of determining whether the patient was nearing the end of life and therefore required specialist palliative care. However, in such cases it is also possible that sedation is administered prematurely. On this basis, the Guideline for Palliative Sedation makes reference to the possibility of using intermittent sedation as a way of determining the true condition of the patient.⁷³ It also proposes that this form of sedation gives the doctor an opportunity 'to evaluate the situation with the patient and/or family and if necessary to review the management of the case'.⁷⁴ This suggests that the Guideline aims to encourage palliative care appropriate to each patient's needs. In these complex situations the Guideline sets out that the input of a consultant, preferably a palliative specialist, is mandatory.⁷⁵ The inclusion of such a requirement begins to highlight the range of parties which may be involved in the decision-making process for the administration of palliative sedation. The inclusion of this requirement for consultation is also an important point in recognising that there are circumstances in palliative medicine where a greater level of expertise is required. Despite this, consultancy is not required in all instances as will be seen when considering the decision-making framework.

69 Janssens (note 43) 665 'Yet, estimating prognosis is often difficult and dependent on several characteristics of the dying phase.'

70 Royal Dutch Medical Association (note 45) 26 'But once a number of characteristics of the phase of dying have been observed, it can be assumed that the patient is approaching the point at which death is inevitable. The most characteristic feature is that patients virtually cease to eat and drink. In addition, they are frequently cachectic, tired and debilitated and bedridden. They may also be drowsy and disoriented. Such signs that a patient is dying, combined with the worsening symptoms of disease, guide the decision-making process.'

71 Ibid. 'The point is therefore not so much to estimate the time until death, but to observe the progress of the signs described above and to conclude that the patient is dying.'

72 See text to note 67 in Chapter 1.

73 Royal Dutch Medical Association (note 45) 27.

74 Ibid.

75 Ibid.

Perhaps, the more significant issue raised by van Delden is whether there is a justification to support the upper limit of two weeks. This aspect of the Guideline appears to be premised on the belief that it would take at least two weeks for a patient to die from dehydration. The lack of clarity on this point was highlighted in Chapter 2. Moreover, the condition of people near the end-of-life is such that their hydration may not be optimal at the point palliative sedation is administered thereby leaving them more susceptible to dehydration. On this basis, van Delden suggests that ‘accepting a two-week limit actually means accepting that the moment of death of at least *some* patients will be determined by the dehydration that comes with continuous sedation (without ANH) and not by the underlying disease.’⁷⁶ The reliance on a two-week prognosis is a questionable basis for defining palliative sedation as normal medical practice. The presence of a refractory symptom and proportional use of sedative drugs is not dependent on a requisite prognosis.⁷⁷ However, it is important to reflect on the basis for the two-week precondition. This requirement does not suggest that all instances of palliative sedation within the timeframe are appropriate or are normal medical practice. Instead, this two-week window could be viewed as establishing a boundary against inappropriate use of palliative sedation outside of this period. This is tied up with the somewhat rigid approach the Guideline takes to the provision of artificial hydration. In addition to this, the Guideline has an impetus to define palliative sedation as normal medical practice and the resulting emphasis on this can result in problems at the periphery of what the Guideline defines as normal. Furthermore, the push to normalise the practice of palliative sedation can result in insufficient attention to aspects which challenge this narrative of care. This is not to suggest that palliative sedation is an exceptional medical practice but that the manner in which the Guideline defines the parameters of palliative sedation may be seen as an attempt to pre-empt criticism from those who would argue that palliative sedation should be made available to patients much earlier in the disease trajectory. To countenance such an expansive use of sedation would be to frustrate the legitimacy of the distinction between palliative sedation and euthanasia.

5.3.3 The decision-making process for palliative sedation

The decision-making process is set out in the fourth chapter of the KNMG Guideline for Palliative Sedation. There are three steps to be taken in making the decision to administer palliative sedation. These stages are; ‘the initial proposal’,⁷⁸ ‘determining whether indications for palliative sedation are present’,⁷⁹ and

⁷⁶ van Delden (note 68) 221.

⁷⁷ Ibid. 222 ‘If the benefit of palliation outweighs the harm of an earlier death, if there are no other reasonable alternatives and if dosages are titrated according to the patient’s need, the imminence condition still remains unaccounted for. Refractory symptoms are conditional for continuous sedation, not the moment when these occur.’

⁷⁸ Royal Dutch Medical Association (note 45) 28.

⁷⁹ Ibid.

‘consultation with the patient and/or his representative(s)’.⁸⁰ These stages are not isolated and may need to be repeated in certain circumstances.⁸¹

The possibility of administering palliative sedation can be broached in several ways. A direct or indirect request to relieve suffering may be made by either the patient and/or her family. It may be that staff involved in providing care to the patient raise the prospect of palliative sedation. This, of course, depends on the condition of the patient and the likely trajectory of their illness. Once the initial proposal for palliative sedation has been raised then it is necessary to assess the patient’s condition while taking account of the indications and preconditions for palliative sedation as set out in chapter 3 of the Guideline.

The process underlines the importance of taking account of all the parties involved in the provision of palliative care such as the nursing staff who have ‘regular close contact with the patient’.⁸² Information is also to be collected from the patient, other healthcare professionals, and the patient’s family in order to ascertain the most appropriate approach to the care of the patient. The value of information from healthcare staff involved in the care of the patient is recognised in the Guideline for Palliative Sedation which sets out that ‘nursing staff and other carers can frequently provide background information in support of the expressed desire or need for sedation. From this information a picture can be built up of the patient’s overall situation, in terms of case history, diagnosis and prognosis’.⁸³ The Guideline recognises that many healthcare professionals will interact with the patient over the course of an illness and it is therefore important that there be effective cooperation and communication between these carers; a task which is not always achieved. In this way, there can be consistency in the care of the patient thereby reducing any apprehension or uneasiness on the part of the patient, their family, and healthcare professionals. The decision-making process is required regardless of whether the patient is receiving palliative care in a hospital or whether they are being cared for in the home. It highlights the importance of ‘clear agreements ... between all concerned’.⁸⁴ This requires effective transfer of information between healthcare staff and means that they need to share a common understanding of specialist palliative care practices. The final decision on palliative sedation is made by the attending physician. The Guideline for Palliative Sedation sets out that the decision is to ‘specify the aim of sedation ..., its nature ..., the choice of drugs, and the dose to be administered’.⁸⁵ The possibility of requiring consultation with an expert in palliative care is also addressed in the Guideline.

80 Ibid.

81 Ibid. 28 ‘The committee wishes to make the general observation that these stages are not one-off activities or decisions. Far more frequently, they are steps in a longer journey of palliative and other care. Some of the steps in that journey will have to be repeated.’

82 Ibid. 29.

83 Ibid.

84 Ibid.

85 Ibid. 30.

A requirement to consult a palliative specialist?

The nature of consultation or professional oversight perhaps has shadows of Regional Review Committees in the Netherlands. Such a resemblance would be unwelcome given the background and purpose of the Guideline but this should not impinge on the appropriate care of the patient. On this subject, the Guideline for Palliative Sedation sets out that:

given the nature and content of palliative sedation and the medical indications set forth in this guideline, the committee sees no need to insist that an expert physician be consulted at all times before deciding to administer palliative sedation.⁸⁶

Yet, the Guideline suggests that if a doctor is uncertain about his own expertise or finds it challenging to balance the various considerations which are part of deciding whether to provide palliative sedation then it is common professional practice to consult with an appropriate expert in the area. To seek the advice of a consultant in such an instance is described as ‘a general principle of medical practice’.⁸⁷ Notwithstanding this, the Guideline subsequently illustrates a degree of tension in maintaining the simple classification of palliative sedation as normal medical practice as it described the practice as a ‘radical medical procedure, since it lowers the patient’s level of consciousness until the moment of death’.⁸⁸ The Guideline strives to achieve a decision-making process which pays heed to the impact of palliative sedation on a patient while attempting to distinguish the decision-making process from that implemented under section 2 of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001.

Research on the level of consultation which occurs suggests that the number of cases in which the opinion of an expert is sought is not high. In a 2008 study by Rietjens et al. it was shown that palliative consultation occurred in 9% of cases and consultation was most regularly sought by general practitioners, 20%.⁸⁹ It would be harmful to the care of the patient if consultation is largely avoided in an effort to emphasise that palliative sedation is normal medical practice. This point is underlined by the link identified in the research between palliative consultation occurring and subsequent appropriate drug use.⁹⁰ The role of consultation in deciding to administer palliative sedation has also been drawn out in research conducted by de Graeff et al.⁹¹ This study revealed that in ‘41% (47 out of 113) of the cases where the palliative consultation team of the Integral Cancer Center for

86 Ibid.

87 Ibid.

88 Ibid.

89 J. Rietjens and others, ‘Continuous deep sedation for patients nearing death in the Netherlands: descriptive study’ (2008) 7648(336) *British Medical Journal* 810.

90 Ibid.

91 A. de Graeff, ‘De rol van consultatie bij palliatieve sedatie in de regio Midden-Nederland’ (2008) 152 *Ned Tijdschr Geneesk* 2346 quoted in Janssens (note 43) 667.

Central Netherlands was consulted on palliative sedation, a negative advice was given.⁹² The reasons for such advice included symptoms not being considered refractory or that life expectancy exceeded two weeks. The high percentage of cases where palliative sedation was deemed inappropriate suggests that consultancy is an important safeguard both in protecting a patient's human rights and in maintaining the distinction between palliative sedation and euthanasia. These figures could also be understood as suggesting that consultation was sought in complex decisions which required the input of an expert in palliative care. This generous interpretation would suggest doctors are judicious about seeking consultation. Unfortunately, such an interpretation is questionable considering a study of Dutch physicians conducted by Swart et al.⁹³

Earlier discussion in this Chapter and in Chapter 1 highlighted that illnesses such as COPD pose additional challenges in determining when it is appropriate to commence palliative sedation. It may often be more difficult to determine if the patient is nearing the end of life and is imminently dying. The Guideline for Palliative Sedation described consultation, preferably with a palliative specialist, as mandatory in situations where there is some degree of doubt about the indications for palliative sedation. In the research by Swart et al. it was noted that for non-cancer patients it was less likely that there would be consultation with a palliative care team prior to the administration of sedation than compared with cancer patients (10% in contrast to 27%).⁹⁴ This is somewhat surprising given the additional decision-making burdens presented by non-cancer patients. In spite of this, consultation was perceived as being helpful in 89% of cases, for both cancer and non-cancer patients.⁹⁵ It may then be expected that the use of consultation is perceived as good medical practice by bodies such as the European Association of Palliative Care⁹⁶ and the American Medical Association.⁹⁷

As mentioned at the start of this section, consultation raises an undesired association with the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001. However, it is clear from the research cited that assessing whether the indications for palliative sedation are present requires considerable expertise. The Guideline for Palliative Sedation requires consultation where there are concerns about the indications present but the decision largely rests with the physician. In effect, the physician must be able to identify and acknowledge circumstances where they do not have sufficient expertise to make a final decision without appropriate support. As decisions will be made by palliative specialists as

92 Ibid.

93 S.J. Swart and others, 'Continuous palliative sedation for cancer and noncancer patients' (2012) 43(2) *Journal of Pain and Symptom Management* 172.

94 Ibid. 175.

95 Ibid.

96 N.I. Cherny and others, 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care' (2009) 23(7) *Palliative Medicine* 581.

97 American Medical Association, 'The AMA Code of Medical Ethics' opinion on sedation at the end of life' (2013) 15(5) *American Medical Association Journal of Ethics* 428.

well as general practitioners who are less likely to be regularly confronted with such a decision, it is understandable that the Guideline does not make consultation mandatory in all instances.⁹⁸ Janssens considered the approach taken in the Guideline and suggested that the basis for leaving the discretion with the individual physician did not stem from concern about good care but instead was based on distinguishing palliative sedation from euthanasia.⁹⁹ This is the crux of the issue. A requirement for mandatory consultation might appear to edge palliative sedation away from normal medical practice but seeking a second opinion is sound medical practice. It is a practice which regularly occurs in other aspects of medicine. Here too, the approach taken in the Guideline has sought to emphasise normal medical practice to a point which appears disproportionate. On this matter, it is worth citing Janssens in that '[c]onsultation (whether mandatory or optional) and normal medical treatment are not mutually exclusive'.¹⁰⁰ The patient at the end of life is deeply vulnerable and decisions should be made in a way which promotes good care rather than concentrating on the external perception. As such, it is to be questioned whether alternative treatments are occasionally missed by virtue of a reluctance to seek consultation. Despite this, broader consultation will often be required. This involves seeking the views of a range of people as part of the decision-making process. The views of the patient are particularly important due to the right of autonomy, and the discussion with the patient and/or their representative on the possibility of palliative sedation has been assigned guidelines detailing what issues are to be addressed over the course of several conversations.

Discussion with the patient and/or his representative

The informed consent of a patient is necessary for the administration of palliative sedation, as was noted in the preceding Chapter, but if the patient is not capable of making an informed decision then a representative of the patient must be consulted. The possible representatives of the patient are set out by the Medical Treatment Contracts Act in the Netherlands.¹⁰¹ This legislation serves to establish an order of eligibility for the representation of a patient. The Guideline for Palliative Sedation addresses the different situations which are likely to arise and

98 Janssens (note 43) 667 'As meticulous assessment of refractoriness of symptoms is necessary, expert consultation before palliative sedation is part of good care. This does not mean that consultation should become mandatory in The Netherlands.'

99 Ibid. 'It does mean, however, that the reason the guideline provides for leaving consultation an individual responsibility of the physician does not come from a consideration of good care, but is the result of the guideline's key message that palliative sedation should be distinguished from euthanasia.'

100 Ibid.

101 Royal Dutch Medical Association (note 45) 33 In order of eligibility: the patient's legal representative (a guardian or mentor appointed by the Court), if he has one; whom failing a personal representative; whom failing his spouse, partner or companion; whom failing a parent, child, brother or sister. See (Article 7:465 of the Dutch Civil Code).

provides guidance on the discussion which is to take place. In relation to discussion with the patient, the Guideline suggests that the consent of a patient should be 'sought while the patient is still lucid'.¹⁰² This requires healthcare professionals to be proactive in engaging and discussing care options with the patient from an early stage in the disease trajectory. Discussion with the patient is to include an explanation of palliative sedation. This allows the patient to understand their prognosis and the impact which palliative sedation would have on them.¹⁰³ The second category for discussion involves the 'Specific wishes and views of the patient'.¹⁰⁴ This allows the patient to discuss their concerns or anxieties about the dying process, their views on organ donation, spiritual care, and physical care during palliative sedation.¹⁰⁵ Discussion on these points may serve to ease the anxiety of the patient and lessen the need for sedation once a patient's concerns are addressed. The third category addresses issues such as the provision of 'support for the patient's family'.¹⁰⁶ This underlines the breadth of the decision-making process and the clarity in communication between doctor and patient which is required in the Netherlands. These are important steps to take in respecting the patient's right of autonomy. For example, Beauchamp and Childress set out that respect for autonomy in medical care 'requires much more than avoiding deception and coercion. It requires an attempt to instill relevant understanding, to avoid forms of manipulation, and to respect persons' rights'.¹⁰⁷

The KNMG Guideline also provides for situations where the patient may lack the necessary capacity to make decisions relating to their healthcare. Depending on the condition of the patient it may be necessary that the discussion be had with the patient's representative instead of the patient. However, in such cases it is still necessary that the patient be involved in the decision-making process as much as possible.¹⁰⁸ This discussion is based on the same issues as set out above and concentrates on the interests of the patient. In any case it appears that the doctor has the final say in the administration of palliative sedation and it is possible that the opinion of a representative be ignored and palliative sedation provided without consent if necessary. As the discretion rests with the physician there are undertones of medical paternalism as to how the decision is reached.¹⁰⁹ Nevertheless, the

102 Ibid. 31.

103 Ibid. 32 The issues to be discussed include: 'The patient's condition, life expectancy and prospects', 'The indications for and purpose of palliative sedation', 'The options in the case of unbearable and untreatable suffering', and 'The consequences of palliative sedation.'

104 Ibid.

105 Ibid.

106 Ibid. 32–33.

107 T.L. Beauchamp and J.F. Childress, *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013) 121.

108 Royal Dutch Medical Association (note 45) 33.

109 Beauchamp (note 107) 122 If shared decision making is presented as a plea merely for patients to be allowed to participate in decision making about diagnostic and treatment procedures, it continues the legacy of medical paternalism by ignoring patients' rights to consent or to refuse those procedures.

Guideline for Palliative Sedation sets out that '[a]s a rule ... it is extremely important that a consensus should be reached between medical staff and the patient's family about the aim of the treatment (to relieve suffering and not to shorten life), the procedure that is appropriate to achieve this, and the consequences that it is likely to have.'¹¹⁰ Circumstances can arise where such consultation is not possible due to a rapid deterioration in the patient's condition and sedation must be administered in the absence of consent from the patient or their representative. In such a scenario responsibility for the decision will often rest with the attending physician.

The decision to administer sedation is not the only decision which will arise. On this point, part of the procedure in relieving a patient's suffering may be the withdrawal of artificial nutrition and hydration. The legal and ethical issues this raises have been set out in several chapters of this work so far and the manner in which the Guideline for Palliative Sedation address the administration of fluids is especially important in recognising and establishing the demarcation between specialist palliative care practices and euthanasia.

5.3.4 The administration of fluids in palliative care

The Guideline for Palliative Sedation adopts a clear position on the administration of fluids. Provided that the patient has a prognosis of one to two weeks then hydration is 'not a relevant factor'¹¹¹ in decisions about palliative sedation. Nonetheless, the Guideline addresses situations where the patient is able or unable to take fluids or even refuses the administration of fluids. It sets out that for patients who are able to take fluids and wish to continue doing so then 'superficial, brief or intermittent palliative sedation is a possible alternative'.¹¹² Such patients would not receive continuous sedation as this would result in them being deprived of hydration. The Guideline set out a number of factors which are to be considered in deciding whether to withhold hydration from a patient who is unable to take fluids. The general guidance on this issue is that when palliative sedation is being administered it is futile to also provide fluids.¹¹³ Treatment is considered futile in circumstances where the resources required exceed the possible benefits of the treatment.¹¹⁴ On this point, the Guideline suggests that the provision of artificial hydration could 'prolong suffering or exacerbate it by increasing oedema, ascites, bronchial secretions, urine production and incontinence'.¹¹⁵ In contrast to

110 Royal Dutch Medical Association (note 45) 33.

111 Ibid. 35.

112 Ibid. 36.

113 Ibid.; J.G.J. Hasselaar and others, 'Changed patterns in Dutch palliative sedation practices after the introduction of a national guideline' (2009) 169(5) *Archives of Internal Medicine* 430, 436.

114 Royal Dutch Medical Association (note 45) 36. 'the resources involved unreasonably outweigh the potential benefits of the treatment'.

115 Ibid.

this, the literature reviews cited in Chapter 2 did not identify such a clear position on the withdrawal or withholding of artificial nutrition and hydration.¹¹⁶

The Guideline for Palliative Sedation underlines the distinction between decisions to provide sedation and to withhold hydration, for example, '[t]he decision-making regarding fluids is in all cases a separate decision, which precedes the decision to initiate continuous sedation.'¹¹⁷ This approach seems to cloud the distinction between the practices which the Guideline seeks to emphasise; while they may be considered separate decisions they are closely linked. In effect, sedation cannot be administered until a decision on the withdrawal of hydration has been taken, i.e. '[t]he actual initiation of continuous sedation will therefore only take place once the patient has decided to refuse fluids, has shown consistency in this respect, *and* exhibits a refractory symptom.'¹¹⁸ As such, the decision-making process for administering palliative sedation requires the question of withdrawing or withholding hydration from the patient to be addressed. The KNMG appears to be distinguishing palliative sedation from euthanasia on narrow ground in the Guideline. For example, the Guideline states that:

The committee would emphasise that two distinct decisions are involved here, which are taken together, but where the key lies in the initial decision by the patient himself. The order in which the decisions are taken and the existence of an interval between the two separate decisions are crucial.¹¹⁹

The fact that these decisions are so closely related is problematic in fully demarcating the role of specialist palliative care. It can be said to leave room for accusations that specialist palliative care is a form of euthanasia in disguise.¹²⁰ However, the Guideline does recognise the problems these decisions raise and places a special emphasis on the correct decision-making process. This encourages consistency among healthcare professionals and across healthcare facilities which provide specialist palliative care. In effect, by recognising and addressing the complex decisions which doctors face on a day to day basis it is possible to remove the image of decisions being taken on an ad hoc basis. This is an important step in protecting the rights of a patient, providing clarity to healthcare professionals, and distinguishing palliative sedation from euthanasia. In line with this, the Guideline clearly categorises artificial hydration as a 'medical procedure'¹²¹ rather than a form of medical care.

116 Text to note 146 in Chapter 2.

117 Royal Dutch Medical Association (note 45) 36.

118 Ibid. 37 (emphasis in original).

119 Ibid.

120 J.A. Billings and S.D. Block, 'Slow euthanasia' (1996) 12 *Journal of Palliative Care* 21; B.M. Mount, 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes' (1996) 12 *Journal of Palliative Care* 31; H. Brody, 'Commentary on Billings and Block's "Slow Euthanasia"' (1996) 12 *Journal of Palliative Care* 38; S. Gevers, 'Terminal sedation: a new legal approach' (2003) 10 *European Journal of Health Law* 359, 360.

121 Royal Dutch Medical Association (note 45) 37.

5.3.5 The administration of palliative sedation

Chapter 6 of the Guideline for Palliative Sedation focuses on issues relating to the administration of palliative sedation such as ‘the preparations to be made, the initiation of sedation, proportionality, the drugs to be used and ... accompanying measures.’¹²² The Guideline for Palliative Sedation goes so far as to specify the type of drug which should be used in palliative sedation as well as providing detail on the amount which should be originally administered, issues of timing, and the approach to be taken for continuous sedation.¹²³ The preparations to be made include informing the professionals involved in the case, and establishing plans for the commencement of sedation as well as subsequent stages of treatment. This demonstrates an awareness that a variety of healthcare professionals are involved in the care of the terminally ill patient. To ensure continuity of care it is vital that healthcare professionals share a harmonious understanding of the type of care which can and should be provided.

The KNMG Guideline recognises the importance of a ‘multidisciplinary approach’¹²⁴ to palliative care and states that ‘[n]ursing staff can contribute important input for drawing up the indications, estimating whether the conditions have been met, and implementing palliative sedation.’¹²⁵ This reflects the substantial role which nursing staff regularly have in the technical administration of palliative sedation.¹²⁶ Although the Guideline recognises the co-operation between healthcare professionals, it is expected that the physician is present at the initiation of palliative sedation. This is a stage when particular challenges can arise which call for a reassessment of the patient’s care plan. On this point, the Guideline sets out that:

Situations may arise in the initial stage in which the physician must be able to intervene (for example, the patient may become delirious or sedation may be too superficial, or indeed too deep). After this, the administration of sedation can be left in large measure to nurses and other carers. They should then be properly informed and instructed, in particular about when to consult the physician.¹²⁷

122 Ibid. 38.

123 Ibid. 39–40. ‘Midazolam is currently regarded as the preferred drug. Arguments in its favour are its short half-life, which means that treatment can be rapidly adjusted, and the considerable experience already gained with it in cases of palliative sedation.’

124 Ibid. 38.

125 Ibid.

126 T. Brinkkemper and others, ‘Palliative sedation at home in the Netherlands: a nationwide survey among nurses’ (2011) 67(8) *Journal of Advanced Nursing* 1719; H.M. Hilden and M.L. Honkasalo, ‘Finnish nurses’ interpretations of patient autonomy in the context of end-of-life decision-making’ (2006) 13(1) *Nursing Ethics* 41; M.J. Evans and C.E. Hallett, ‘Living with dying: a hermeneutic phenomenological study of the work of hospice nurses’ (2007) 16(4) *Journal of Clinical Nursing* 742.

127 Royal Dutch Medical Association (note 45) 39.

This provides practical guidance and gives clarity to the parties involved in the care of the patient. Yet, it appears that prior to and even after the introduction of the Guideline, physicians were not always present at the commencement of sedation. Research by Swart et al. suggests that physicians were in attendance in 81% of cases.¹²⁸ In contrast, a study from the Netherlands which focused on palliative sedation at home highlighted that the general practitioner was not present in a third of cases.¹²⁹ Furthermore, 71% of respondents noted that the general practitioner did not remain until the desired level of sedation was achieved.¹³⁰ Although, a study by Brinkkemper et al. noted that in a majority of cases, 94.5%, it was reported that a general practitioner was available if required.¹³¹ More often it was the nurse who was present at the commencement of palliative sedation.¹³² On this basis, it is important to reflect on whether the Guideline for Palliative Sedation is actually used by healthcare professionals in the Netherlands and what its impact has been.

5.3.6 *The impact of the KNMG Guideline for Palliative Sedation*

There have been several studies which have explored the impact of the KNMG Guideline for Palliative Sedation. These include studies by Hasselaar et al.,¹³³ Brinkkemper et al.,¹³⁴ and Arevalo et al.¹³⁵ Each of these studies concentrates on the period around the introduction of the first Guideline. Consequently, the changes introduced by the second edition of the Guideline are not reflected in the research. This is an important point to bear in mind in considering the limitations of these studies. Despite this, the research provides an insight into

128 S.J. Swart and others, 'Palliatieve sedatie na introductie KNMG-richtlijn' (2011) 155 *Ned Tijdschr Geneesk* A2857 cited in S.M. Bruinsma and others, 'Continuous Sedation Until Death: State of the Art' in S. Sterckx and others, *Continuous Sedation at the End of Life: Ethical, Clinical, and Legal Perspectives* (Cambridge University Press 2013) 44; J.J. Arevalo and others, 'Day-to-day care in palliative sedation: Survey of nurses' experiences with decision-making and performance' (2013) 50 *International Journal of Nursing Studies* 613, 620 'Probably, physicians are selectively absent in cases where nurses bear much responsibility for the initiation and monitoring of palliative sedation. This situation often occurs in the institutional setting where nurses more explicitly operate as members of a team when compared to home care.'

129 Brinkkemper (note 126).

130 Ibid. 1722; Arevalo (note 128), 618 'According to the respondents, physicians were present until the desired sedation level was achieved in 11.05% of cases.'

131 Brinkkemper (note 126) 1719.

132 Arevalo (note 128) 617–618 'Nurses were frequently present at the start of the sedation (81.40%); relatives (52.76%) and physicians (45.22%) were less often present. Physicians were less often present in nursing homes/hospices (37.03%) and hospitals (42%) when compared to home care (61.22%, $p = 0.03$); no difference was found with regard to the presence of relatives at the start of the sedation between settings.'

133 Hasselaar (note 113).

134 Brinkkemper (note 126).

135 Arevalo (note 128).

decision-making in practice, the reference to guidelines, and the administration of palliative sedation.

In the study by Hasselaar et al., a baseline measurement was taken between 1 February 2003 and 1 May 2005. This involved 492 physicians including medical specialists, general practitioners, and nursing home doctors. After the national guideline for palliative sedation was introduced a follow-up study was conducted between 1 January 2007 and 30 June 2007. The follow-up study was based on the 492 physicians in the baseline measurement. It asked these physicians to report on the last occasion they provided continuous deep sedation in the past 12 months. The Brinkkemper et al. study concentrated on the experience of medical technical assistance nurses who were involved in the administration of palliative sedation in a home setting. Similarly, the study by Arevalo et al. focused on the experience of nurses in home care settings, nursing homes, in-patient hospices, and hospitals in the Netherlands. The combination of these studies provides for a rounded perspective on the functioning of the first edition of the Guideline as well as facilitating cross-comparison of research findings.

Familiarity with the KNMG Guideline for Palliative Sedation

The use of guidelines by medical practitioners in the Netherlands has increased in the past number of years. 60.1% of doctors in 2007 referred to some form of guideline when sedating a patient.¹³⁶ Although this figure may appear low, it represents a doubling in the use of guidelines since 2003.¹³⁷ Of particular importance for this work is the fact that 78.1% of doctors who administered palliative sedation had knowledge of the KNMG Guideline.¹³⁸ 90.7% of respondents in Brinkkemper et al. were aware of the Guideline while 47.3% rated their knowledge of the Guideline as good or excellent. As there has been a second edition of the Guideline published in the interim, as well as other guidelines on palliative care published by Comprehensive Cancer Centre the Netherlands, it is likely that familiarity with the Guideline will have increased further. In any case, it appears that as of 2007 the KNMG Guideline was already having an impact on the provision of palliative care in the Netherlands.

Decision-making for palliative sedation

The results of the study by Hasselaar et al. demonstrated a rise in patient involvement in decision-making. For example, patient involvement increased from 72.3% to 82.2% between the two periods.¹³⁹ Advance discussion of sedation

136 Hasselaar (note 113) 432; Swart (note 93), 175–176 ‘The use of a guideline for continuous sedation did not differ significantly between noncancer (61%) and cancer (64%) patients.’

137 Hasselaar (note 113) 432.

138 Ibid. Note that higher percentages do exist depending on the area of practice. 83.9% of medical specialists reported familiarity with the KNMG guideline while this figure stood at 67.2% for general practitioners and 90.3% for nursing home physicians.

139 Ibid.

between the patient and physician rose from 40.1% to 49.3%.¹⁴⁰ While the percentage of physicians who did not discuss sedation with the patients dropped from 27.6% to 17.8%.¹⁴¹ In line with these figures, Brinkkemper et al. found that 86.5% of nurses reported that the patient or their representative received appropriate information about the aim and practice of palliative sedation.¹⁴² It appears that increased discussion may be having an impact on the number seeking euthanasia or physician assisted suicide. It has been suggested that the fear of pain often 'leads to suicide ideation or the request for euthanasia' and encourages 'public support for assisted-suicide and euthanasia'.¹⁴³ This fear may be partly addressed through discussion with the patient so they are familiar with the level of care they will receive, should they need it. Since the introduction of the KNMG Guideline there was a decrease in patient's requests for euthanasia. In the first period, the figure requesting euthanasia amounted to 14.5% while in 2007 this figure had dropped to 6.3%.¹⁴⁴ As such, clear guidelines and the discussions on patient care may serve to ease many of the fears patients have near the end of life.¹⁴⁵ Hasselaar et al. also advanced the argument that this change in figures might simply represent a 'more straightforward patient preference for palliative sedation at the end of life'.¹⁴⁶

Research has shown that continuous deep sedation was being administered more often in 2010 than it had been in 2005.¹⁴⁷ This, of course, leads to further claims that palliative sedation is instead being used to sidestep the criteria for

140 Ibid.

141 Ibid.

142 Brinkkemper (note 126) 1723 'A vast majority of respondents (95.3%) believed that the last patient had received sufficient guidance by themselves, colleagues or the GP (81.8%).'

143 S.A. Fohr, 'The double effect of pain medication: separating myth from reality' (1998) 4(1) *Journal of Palliative Medicine* 315, 326.

144 Hasselaar (note 113) 432; Arevalo (note 128) 617 'According to nurses, a formal euthanasia request was made by 48.27% (N = 28) of patients. A formal euthanasia request refers to the situation in which the patient explicitly requests the physician for the administration of medications with the explicit intention of hastening death (van der Heide et al., 2007). In most cases euthanasia was not performed because immediate symptom relief was required and there was thus no time to proceed with a euthanasia request (N = 12).'

145 The alternative interpretation of these figures is to suggest that doctors view specialist palliative care as being in some way more acceptable than euthanasia and that it is on this basis that specialist palliative care is favoured. Were such a criticism shown to be true it could have serious consequences for the distinction between specialist palliative care and physician assisted suicide.

146 Hasselaar (note 113) 436.

147 B.D. Onwuteaka-Philipsen and others, 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey' (2012) 380(9845) *Lancet* 908, 908 'Continuous deep sedation until death occurred more frequently in 2010 (12.3%) than in 2005 (8.2%). Of all deaths in 2010, 0.4% were the result of the patient's decision to stop eating and drinking to end life; in half of these cases the patient had made a euthanasia request that was not granted.'

euthanasia. Brinkkemper et al. illustrated a high level of confidence, 92.7%, among nurses that the indications for palliative sedation were present.¹⁴⁸ Likewise, respondents in the Arevalo et al. study agreed with the administration of palliative sedation in 95.97% of cases.¹⁴⁹ Although these figures are high it does leave a small number of cases where there is some disagreement as to the most appropriate course of treatment. As nurses are regularly present at the start of sedation and have an ongoing role throughout the process it is important that they be involved in these decisions and in subsequent discussions. Arevalo et al. suggested that nurses felt involved in the decision in 84% of cases although this was slightly lower, 68.75%, for palliative sedation in the home.¹⁵⁰ Arrangements for ongoing cooperation and coordination were made in 72.77% of cases.¹⁵¹ Whereas 20% of respondents in Brinkkemper et al. stated that no measures were established for nurses and physicians to keep each other informed of sedation policy. This is a significant shortcoming and represents an avoidable hindrance in the care of the patient. Ongoing cooperation between healthcare professionals is essential as it reflects the fact that palliative sedation is a process rather than a single decision.

The increased prevalence of continuous deep sedation has more recently been highlighted in a 2015 study on end-of-life decision-making in the Netherlands.¹⁵² The study suggests that continuous deep sedation was administered in 18.3% of cases in 2015. This is a significant increase over the 2005 figure of 8.2%. It adds to the concerns that sedation is being used in a manner intended to avoid the oversight attached to cases of euthanasia. Further research is required in this area to identify the underlying factors which have brought about this increase.

The administration of palliative sedation

Hasselaar et al. highlighted a significant increase in the use of benzodiazepines for sedation rather than use of morphine.¹⁵³ This is in line with recommendations

148 Brinkkemper (note 126) 1722.

149 Arevalo (note 128) 616. In 16.16% of cases continuous palliative sedation was proposed by nurses.

150 Ibid.

151 Ibid. 618.

152 A. Van der Heide and others, 'End-of-Life Decisions in the Netherlands over 25 Years' (2017) 377 *New England Journal of Medicine* 492.

153 Hasselaar (note 113) 433 'benzodiazepines were more often prescribed for continuous sedation after the introduction of the guideline than before (69.9% and 90.4%, respectively) ... A similar use of benzodiazepine combined with morphine was prescribed before (51.9%) and after the introduction of the guideline (51.9%), whereas the use of benzodiazepine without morphine increased after the introduction of the guideline (from 30 [18.8%] to 58 [36.3%]); Arevalo (note 128) 618 'The proportion of patients receiving midazolam increased after sedation was started, whilst the proportion of patients receiving opioids decreased reflecting that opioids were not a core medication used for palliative sedation.'; Similar changes in Italy where there were no guidelines F. Bulli and others, 'Continuous deep sedation in home palliative care units: case studies in the Florence area in 2000 and in 2003–2004' (2007) 73(5) *Minerva*

contained in the Guideline.¹⁵⁴ The reason for favouring benzodiazepines as a sedative is due to the ‘unpredictable sedative and side effects’¹⁵⁵ of morphine. A high use of midazolam for sedation, 73.6%, was also reported by the respondents in Brinkkemper et al.¹⁵⁶ Yet, it was also highlighted that in 13% of cases there were problems in the use of medication. This included delirium, agitation, and problems such as toxicosis due to morphine use. The availability of appropriate palliative medicines was also a concern raised by Brinkkemper et al. In 17.2% of cases palliative medications were not always available. This may be due to timing such as out of hours access at night time or during weekends.¹⁵⁷ The study by Arevalo et al. also underlined this shortcoming in home care. Although respondents reported that medications were available in 94.94% of cases and medical equipment was accessible in 93.90% the figures for home care settings were much lower, 83.67% and 87.75% respectively.¹⁵⁸ This is an issue which is beyond the scope of a Guideline alone and raises human rights issues such as those discussed in Chapter 3. It requires action at an institutional level if an effective remedy is to be identified and implemented.

The provision of fluids is a closely related but distinct practice from palliative sedation. There is little information on the withholding or withdrawal of artificial hydration in either Brinkkemper et al. or Arevalo et al. Fortunately, Hasselaar et al. examined this issue. There is a substantial divergence in the figures between the two periods examined in this study. In the first period, 56.3% of physicians decided not to provide artificial hydration but this figure increased to 78.8% of physicians in 2007.¹⁵⁹ The median survival time for patients was two days in both periods.¹⁶⁰ Although, the median survival time did not change it is striking that artificial hydration was not provided in so many additional cases. This approach is in line with the Guideline but it raises questions about the appropriateness of such a policy especially as individualised assessment and care of the patient has such an important role in palliative care.

5.3.7 Normal medical practice: a sufficient justification?

The KNMG Guideline set out to distinguish palliative sedation from euthanasia through defining palliative sedation as normal medical practice. Therefore, it is to be questioned whether the Guideline has been effective in doing so and, in turn, does the Guideline provide an appropriate justification for the practice of palliative sedation? This chapter has highlighted several weaknesses in the content of the

Anesthesiol 291; Van der Heide (note 152) ‘this practice involved the use of benzodiazepines, often combined with an opioid, in 83% and 95% of all cases, respectively.’

154 Royal Dutch Medical Association (note 45) 40.

155 Rietjens (note 89) 6.

156 Brinkkemper (note 126) 1722.

157 Ibid. 1723.

158 Arevalo (note 128) 618.

159 Hasselaar (note 113) 433

160 Ibid.

Guideline, including the requisite prognosis, the administration of fluids, the possibility of consultation, and the role of the nurse and other healthcare professionals.

The Guideline establishes the precondition that the patient has a life expectancy of no more than two-weeks. This requirement is predicated on the potential for dehydration to occur when palliative sedation is administered outside of this timeframe. As such, while the focus is placed on the prognosis it is the approach to the administration of fluids which is perhaps more problematic and which is the motivating factor for the prognosis. The Guideline describes artificial hydration as futile and practically defines the default position as the withholding of artificial hydration. This certainly appears to be the effect of the Guideline as demonstrated in the research cited above from Haaselaar et al. In chapter 1 it was highlighted that the decision to withhold or withdraw artificial hydration does not lend itself to identifying a universal approach.¹⁶¹ Instead, the provision of artificial hydration must be assessed on a patient-by-patient basis. The impetus to define palliative sedation as normal medical practice has resulted in attempts to control aspects of practice which may prove more clinically and ethically complex than the Guideline suggests. The result of this is to obfuscate the legitimacy of treatment provided at the bounds of what the Guideline frames as normal medical practice. Consequently, aspects of practice which require particular attention and guidance are neglected due to the focus on normal medical practice. A similar issue arises in the context of consultation.

The decision to consult another physician, preferably a palliative specialist, largely rests with the attending physician. It has been suggested that consultation is not mandatory as it would narrow the distinction between palliative sedation and euthanasia and therefore make it more difficult to define as normal medical practice. However, as noted above, care will often be provided by palliative specialists who have sufficient knowledge and further consultation may not be necessary. There is therefore a valid basis for leaving this decision to the discretion of the physician. This does however highlight additional aspects of the Guideline which do not necessarily impinge on the categorisation of the practice as normal medical practice but which nonetheless illustrate certain failings in the Guideline.

Much of the Guideline discusses sedation as if it is a once off decision or practice. Rather, it is a process which includes the periods before and after sedation is commenced. Sedation must be monitored and adjusted accordingly. This perspective demonstrates a more nuanced practice which the Guideline does not fully capture. During the process of palliative sedation, a range of healthcare professionals will be closely involved in the care of the patient. The Guideline acknowledges the importance of cooperation and information sharing but does not fully reflect the substantial contribution of the nursing profession. Brinkkemper et al. highlighted how in 14.9% of cases it was the nurse who made an independent

161 M.A.C. Pinna and others, 'Sedación en Cuidados Paliativos' (SECPAL, 2005); S. Dalal and others, 'Is there a role for hydration at the end of life?' (2009) 3(1) *Current Opinion in Supportive and Palliative Care* 72.

decision about dosage policy.¹⁶² Moreover, Arevalo et al. recommended that nurses ‘become more active participants in the decisionmaking to improve the care of patients receiving continuous palliative sedation’.¹⁶³ As nurses are regularly involved in the decision-making process they can serve as an extra check on the decision to commence sedation.

The approach taken by the Guideline tends to describe a practice which neatly fits within clearly defined parameters. Palliative sedation is not this type of practice. It is part of a form of care which raises challenging issues and addresses the symptoms and needs of each individual patient. It does not treat all patients alike. Patients will present with different aetiologies, different disease trajectories, and different personal concerns and values. Consequently, it is to be expected that challenging decisions must be made. This alone does not transform a medical practice from being normal and justified to being extraordinary. Overall, the KNMG Guideline represents an important part of the framework for specialist palliative care in the Netherlands. It has contributed to the development of palliative care, provided greater clarity for all parties, but the question remains as to what the impact of a legislative response would have been.

5.4 Conclusion

Central to this chapter was whether the KNMG Guideline for Palliative Sedation effectively defines palliative sedation as normal medical practice and therefore establishes a legal justification for the practice. The Netherlands provides a unique perspective on the role of guidelines in shaping specialist palliative care. It is a jurisdiction which already permits certain end-of-life practices which are not legally permitted in jurisdictions such as Ireland or England and Wales. On this basis, the Guideline is an attempt to define the space between the practice of palliative sedation and euthanasia. In many respects, the KNMG Guideline achieves this. It establishes palliative sedation as normal medical practice although there are weaknesses in the way this is achieved as has been noted above. For instance, there are parts of the Guideline which avoid fully engaging with contentious aspects of the practice. The exclusion of these elements is largely due to the focus on defining palliative sedation as normal medical practice. As such, the Guideline threads a narrow path in defining the legal status of palliative sedation.

Communication and patient involvement in end-of-life decisions can be difficult for all involved.¹⁶⁴ As was outlined in Chapter 3, the goals of palliative care do not sit easily with the traditional liberal conception of autonomy. However, the Guideline marks an important contribution to human rights protection. The decision-making process is set out in the fourth chapter of the Guideline and signals the socially embedded nature of the patient. Decisions are to draw on the input of

162 Brinkkemper (note 126) 1723.

163 Arevalo (note 128) 620.

164 I. Dwyer and J. McCarthy, ‘Experiences of palliative care nurses in the utilization of palliative sedation in a hospice setting’ (2016) 6 *End-of-Life Journal* 1.

a range of people and there is concern for the patient's family. This reflects the goal of palliative care in improving the quality of life for patients and their families. Patient autonomy is promoted through requirements to explain palliative sedation, to discuss the specific wishes and views of the patient, and to question whether particular support measures are needed for the patient's family. Furthermore, the Guideline illustrates the need for consent to palliative sedation. The concept of double effect was discussed in Chapter 2 and it is a justification which is largely silent on consent which, in the context of medical treatment, is an essential component. On this point the Guideline encourages early engagement with the patient and suggests consent be sought while the patient is lucid.

Studies cited in this chapter appear to suggest that the Guideline was having a positive impact on the provision of palliative care. There was a good level of familiarity with the Guideline, and a rise in patient involvement in decision-making, although, advance discussion with the patient was still limited to less than one third of cases thereby indicating that there is considerable room for improvement.

The KNMG Guideline is the main guideline which receives attention in academic literature. Nevertheless, it is part of a range of guidelines on palliative medicine which exists in the Netherlands, although, it can be recognised that a majority of these guidelines are not afforded the same legal status. The use of guidelines to establish the legal justification for palliative sedation provides flexibility. It is an approach which can respond to changes in medicine relatively quickly but there are drawbacks to this. It lacks the status and coercive element which attaches to legislation. At the outset it was noted that guidelines were favoured over a legislative approach. The impetus for the 2005 Guideline for Palliative Sedation were the comments of the Dutch Attorney General, Joan de Wijkerslooth. Palliative sedation was administered in 4–10% of all deaths in the Netherlands at the time. The 2015 figure was 18.3%. This raises unavoidable questions about compliance with the Guideline, the administration of palliative sedation in practice, and whether sedation is being used in a manner which sidesteps the due care criteria of the Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001. There are two points which flow from this. First, there is a need for further study on the implementation of the KNMG Guideline for Palliative Sedation so the factors underpinning this increase in sedation are identified. Second, there is a need to return to the suggestion of Joan de Wijkerslooth. Greater legal controls may be necessary owing to the potential criminal law implications arising from injudicious use of palliative sedation. This does not mean that guidelines cannot make a positive contribution towards the legal framework but that stronger compliance mechanisms may be necessary in order to maintain the legitimacy of the distinction between specialist palliative care and physician aided dying. The potential role for legislation will be discussed in the next chapter as France has sought to address debates about end-of-life care by pursuing a legislative agenda which focuses on palliative care.

6 The legal framework for palliative care in France

6.0 Introduction

Each jurisdiction has unique cultural, social, political, geographical, historical, and legal characteristics which are reflected in the legal framework for end-of-life care. In France, there has been a sustained debate about the limits of law at the end-of-life. There have been persistent calls for the liberalisation of the law on euthanasia but the official response is often grounded in the provision of palliative care.¹ This binary approach does not fully express the range of debate and the rationale behind calls for liberalisation. Instead, it suggests that aspects of palliative care can take the place of euthanasia and provide a panacea for dilemmas in medical care. This chapter will explore the ongoing legal discourse on end-of-life care in France. Notably, it is a culture which is informed by a tradition of medical paternalism which stands in contrast to the liberal conception of autonomy which has been prevalent in Ireland, the United Kingdom, and the United States for several decades. Notwithstanding this, recent legislation on end-of-life care in France appears to have vested more autonomy in the patient. This includes a right to refuse treatment as well as a right to actively request palliative sedation. The concerns which guide this chapter are much the same as those which framed discussion in the previous chapter. However, instead of professional guidelines, the focal point is the use of a legislative approach to affect change in the provision of palliative care. It will be argued that legislation can have a significant role but that the use of palliative care legislation to evade political debate on euthanasia is inappropriate regardless of jurisdiction. Drawing on palliative care in such a manner may serve to obfuscate the broader aims and objectives of palliative care.

This chapter is composed of two main sections. First, the background to the provision of palliative care in France will be set out. This will highlight the underlying tension between palliative care and the calls for a change in the legal status of euthanasia. This section will also discuss the conflict between autonomy

1 L. Dany and others, 'Determinants of favourable opinions about euthanasia in a sample of French physicians' (2015) 14 *BMC Palliative Care* 59, 63 'Promoting the development of palliative care is often put forward as an alternative in debates on mooted changes to laws concerning the end of life, with the risk of reinforcing opposition between palliative care organizations and advocates of euthanasia.'

and paternalism in the French healthcare system. It will be argued that this conflict is reflected in the debates on euthanasia and palliative care. Second, the significant legislative milestones for end-of-life care in France will be discussed. This includes law no° 99-477,² law no° 2002-303,³ law no° 2005-370,⁴ and law no° 2016-87 which recognises a right to request palliative sedation.⁵ The two latter pieces of legislation will be examined in detail. In doing so, it will be questioned whether these provide sufficient legal clarity for both the healthcare professional and the patient.

6.1 End-of-life care: an evolving social and legal paradigm

End-of-life care in France can be traced back to Jeanne Garnier who along with two other women established the Association des Dames du Calvaire in Lyon in 1842.⁶ This foundation supported and cared for terminally ill people. A further hospice was established in Paris in 1874 by Aurélie Jousset.⁷ The organisation continued to provide care over the years and in 1971 the Maison Médicale Jeanne Garnier was recognised as part of the French public hospital system.⁸

It was noted in the introduction that palliative care has been closely associated with debates in France about the legal status of euthanasia. However, there was some time between the early calls for greater control over the manner of one's death and the first significant developments in modern palliative care.⁹ While the 1970s brought greater public debate on the care provided at the end-of-life this was often in the context of euthanasia. For instance, Jacques Monod was a signatory to 'A Plea for Beneficent Euthanasia' which was published in 1974.¹⁰ This statement called for people to have more control over the care they receive at the end-of-life and it argued that human suffering should not be viewed as 'inevitable or that little can be done to improve the human condition'.¹¹ The first draft legislation in favour of the legalisation of euthanasia was presented in

2 Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs.

3 Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé.

4 Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie.

5 Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie.

6 D. Clark, *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century* (Oxford University Press 2016) 37.

7 M. Fink, 'France' in R. Gronemeyer, *Helping People at the End of their Lives: Hospice and Palliative Care in Europe* (Lit Verlag 2007) 131. Aurélie Jousset founded the Oeuvre du Calvaire and hospice in Paris.

8 Ibid.

9 R. Horn, 'Euthanasia and end-of-life practices in France and Germany: A comparative study' (2013) 16(2) *Medicine, Health Care and Philosophy* 197, 200 'the palliative care movement gained public attention only a decade later and stayed for a long time on the fringes of the medical community'.

10 (–) 'A Plea for Beneficent Euthanasia' (1974) 34(4) *Humanist* 4. Jacques Monod was a recipient of the Nobel Prize in Physiology or Medicine in 1965.

11 Ibid.

Parliament in 1978.¹² In 1979, an article by Michel Landa appeared in *Le Monde* which presented an argument for a right to die with dignity.¹³ This ultimately led to the establishment of the Association pour le Droit de Mourir dans la Dignité (Association for the Right to Die in Dignity) in 1980.¹⁴ Despite claims for individual sovereignty at the end of life, France remained a strongly paternalistic society in the context of healthcare decision-making.¹⁵ This is in contrast to many Western jurisdictions where there were moves towards greater patient autonomy.

The political response to the calls for liberalisation of the law was often rooted in palliative care and this is evident from the 1980s on. Hennette-Vaucher described the situation as follows, 'one could say that since the early 1980s, efforts have continuously been made to keep the question of active termination of life off the public agenda and to present palliative care as an adequate answer to claims for the legalisation of euthanasia'.¹⁶ Such an approach fails to recognise the variety of motivating factors which underpins calls for a change in the law. In any case, a significant step in developing palliative care in France occurred in 1986 with the publication of the ministerial circular, 'Circulaire Laroque'.¹⁷

'Circulaire Laroque' is the political foundation of palliative care in France.¹⁸ It addressed the provision of palliative care with the aim of improving the dying process and supporting carers and families.¹⁹ The circular highlighted the important role of palliative care in the home which is described as the natural place of life.²⁰ Although emphasis is placed on the role of palliative care in the home the circular recognised that a majority of people die in healthcare facilities.²¹ As a consequence, the circular called for greater provision of palliative care in facilities where most people die.²² Notably, the circular identified a need for palliative care units (USP)²³ and several possible structures were proposed. Detail was provided

12 Proposition de loi n° 301 relative au droit de vivre sa mort présentée par M. Henri Caillavet.; P. Queneau, and G. Osterman, *Soulager la Douleur* (Éditions Odile Jacob 1998) 267; E. Hirsch, *Mort par sedation: Une nouvelle éthique du «bien mourir»?* (Erès 2016).

13 M. Landa, «Un droit» *Le Monde* (17 November 1979).

14 S. Hennette-Vaucher, 'France' in J. Griffiths and others, *Euthanasia and Law in Europe* (Bloomsbury 2008) 372; M. Spranzi, 'The French euthanasia debate: exception and solidarity' (2013) 22 *Cambridge Quarterly of Healthcare Ethics* 254, 255; M. Castra, *Bien mourir: Sociologie des soins palliatifs* (Presses Universitaires de France 2003).

15 E. Ferrand and others, 'Withholding and withdrawal of life support in intensive-care units in France: a prospective survey' (2001) 357(9249) *Lancet* 9, 9.

16 Hennette-Vaucher (note 14) 370.

17 Circulaire relative à l'organisation des soins et à l'accompagnement des maladies en phase terminale, Paris, le 26 août 1986.

18 Gronemeyer (note 7) 131.

19 Circulaire relative à l'organisation des soins et à l'accompagnement des maladies en phase terminale, Paris, le 26 août 1986, 2.

20 Ibid. 3.

21 Ibid. 4; F. Lalande and O. Veber, *La mort à l'hôpital* (Inspection Générale des affaires sociales 2010).

22 Ibid.

23 USP, unité de soins palliatifs.

on the need for multidisciplinary care, the continued availability of curative treatments, and the research and training roles of the USP. In effect, the circular aimed to transform the way people at the end of life are cared for and to therefore bring about a societal change.²⁴

It was in 1987 that the first USP was founded by Dr Maurice Abiven in the Hôpital de la Cité Universitaire in Paris.²⁵ In addition to palliative care units, palliative care in France is provided through the use of identified palliative care beds, mobile palliative care teams, and home hospitalisation teams. The identified palliative care bed is reserved specifically for palliative care in the hospital ward. The bed is not located in a palliative care unit but instead in a ward which is active in palliative care provision and which has established palliative care needs. The mobile palliative care team is a specialised palliative team which provides advice on medical and nursing issues in the delivery of palliative care.²⁶ The home hospitalisation teams often provide care for the patient at the end of life but do not generally provide specialised palliative care.²⁷

During the 1980s several palliative care organisations and charities were established. Jusqu'à la mort accompagner la vie (JALMALV) was set up in 1983,²⁸ and the Association de soins palliatifs (palliative care association) was established in 1984.²⁹ Several of these organisations came together to found the Société Française d'Accompagnement et des soins Palliatifs (SFAP, French Society of Accompaniment and Palliative Care) in October 1989.³⁰ The SFAP aim to disseminate the culture of palliative care through engagement with the public and healthcare professionals. The SFAP have had an important role in the development of palliative care in France since their inception. On this point, the organisation has been described as 'the main interface with public authorities concerning palliative care'.³¹ This work has included contributing to the report on palliative care by Dr Henri Delbecque,³² the proposed establishment of «normes planchers» (minimum standards) for palliative

24 Circulaire relative à l'organisation des soins et à l'accompagnement des maladies en phase terminale, Paris, le 26 août 1986, 8. «Par la généralisation de ces techniques de soins, on peut espérer que l'expérience acquise par chacun, du décès de proches intervenant dans la sérénité et la dignité, entraînera progressivement une transformation des conditions de la mort dans notre société.»

25 Gronemeyer (note 7) 131.

26 Horn (note 9).

27 K. Leichsenring and others (eds), *Long-term Care in Europe: Improving Policy and Practice* (Palgrave Macmillan 2013).

28 M.H. Salamagne and P. Thominet (eds) *Accompagner: Trente ans de soins palliatifs en France* (Editions Demopolis 2015) 85.

29 Ibid. 208.

30 Société Française d'Accompagnement et de Soins Palliatifs, 'Histoire de la SFAP' <<http://www.sfap.org/rubrique/histoire-de-la-sfap>> (accessed 3 September 2017).

31 J.C. Mino and J.M. Mollard, 'The Organisation of Palliative Care in France' in S.H. Ahmedzai and others (eds) *Assessing Organisations to Improve Palliative Care in Europe* (Vantilt Publishers 2010) 146.

32 Société Française d'Accompagnement et de Soins Palliatifs (note 30); H. Delbecque, 'Les soins palliatifs et l'accompagnement des malades en fin de vie' (Ministère des affaires sociales, de la santé et de la ville 1993).

care centres,³³ and the organisation of conferences on palliative care.³⁴ The representative role of the SFAP is particularly important owing to the legalisation of the dying process. Laws on aspects of palliative care began to be introduced from the 1990s on. These laws have also been accompanied by changes to the Code of Medical Ethics published by the Conseil National de l'Ordre des Médecins (National Council of the College of Physicians).³⁵

Law n° 91-748 of 31 July 1991 set palliative care as part of the duty of all hospitals.³⁶ This was a relatively minor element in Law n° 91-748 but illustrated an awareness and recognition of the role which palliative care can have. It conceives of palliative care as a form of care to be incorporated into broader medical practice. This may be challenging for physicians in terms of having sufficient knowledge of palliative care as well as creating a tension between curative and palliative treatments at the end-of-life. At the time of this law, England had already commenced steps towards the recognition of palliative medicine as a medical specialty but it was not until recently that it was recognised as a subspecialty in France. In 2008 a Diploma of Complementary Specialised Studies in Pain Medicine and Palliative Medicine (Diplôme d'études spécialisées complémentaires (DESC) de Médecine de la Douleur et Médecine Palliative) was approved thereby establishing subspecialty status.³⁷ Yet, changes to the Code of Medical Ethics in 1995 underlined an existing focus on pain management.

Article 37 of the Code of Medical Ethics required doctors to relieve patient's suffering in an appropriate manner and to provide the patient with moral support. Article 38 of the Code of Medical Ethics set out that a doctor is not permitted to bring about a patient's death. Horn highlighted a degree of anxiety amongst doctors on the interpretation of Articles 37 and 38 and suggests that this ambiguity resulted in a strong preference for life-prolonging treatment.³⁸ There was a distinct reluctance to move from cure to care near the end of life. This was tied up with conceptions of medical paternalism in France which meant that the voice of the patient was not always heard. Subsequent laws on palliative care have navigated a difficult path between patient rights and the legal protection of healthcare professionals. However, the friction between autonomy and medical paternalism has endured.

33 Société Française d'Accompagnement et de Soins Palliatifs (note 30).

34 Ibid.

35 Conseil national de l'Ordre des médecins, 'Code de Déontologie Médicale' (avril 2017).

36 Loi n° 91-748 du 31 juillet 1991 portant réforme hospitalière. «Ils dispensent aux patients les soins préventifs, curatifs ou palliatifs que requiert leur état et veillent à la continuité de ces soins, à l'issue de leur admission ou de leur hébergement.»

37 D. Bolognesi, 'Specialisation in Palliative Medicine for Physicians in Europe 2014: A supplement of the EAPC Atlas of Palliative Care in Europe' (EAPC 2014) 19.

38 Horn (note 9) 201 'the resultant uncertainty served to maintain an attitude in favour of life prolongation at "any price", in the sense of "by means of any therapeutic investigation".'

6.1.1 The conflict of autonomy and medical paternalism

Central to healthcare decision-making is the concept of consent, capacity, and effective communication between the physician and the patient. In this respect, the requirement for informed consent in medical treatment is clear in France. The requirement for informed consent may arise through the contractual nature of the physician–patient relationship,³⁹ it has been recognised as an element of the ‘respect for the human person’,⁴⁰ and it has been ‘linked to the constitutional principle of human dignity’.⁴¹ Despite the law on informed consent being clear the actual application in practice has often been problematic.⁴² Respect for the patient’s decision may be challenged in treatment-refusal decisions particularly in circumstances where the withholding or withdrawal of treatment could bring about the death of the patient. This sense of paternalism is demonstrated by the *Garnier*⁴³ and *Senanayake* cases.⁴⁴ In *Garnier*, the patient’s refusal of treatment was ignored by the Conseil d’État. In the *Senanayake* case a refusal of a blood transfusion by a Jehovah’s Witness was not followed by doctors treating the patient.

Unlike the culture of healthcare decision-making in England and Ireland which emphasises the status of patient autonomy, the approach in France ‘reflects a culture promoting the protection of the vulnerable person, even if this is to the detriment of the person’s autonomy’.⁴⁵ Horn suggests that this approach can be traced back to Rousseau’s social contract.⁴⁶ On this basis, ‘every individual’s opinions and preferences are subject to the general will which represents the interests of the community as a whole’.⁴⁷ This results in a paternalistic approach which views the role of the physician as an agent of the community who is entrusted with defending and promoting societal values. In establishing the physician as the arbiter of such decisions it places the patient in a position where they have a moral obligation to accede to the doctor’s instructions.⁴⁸ It is a relationship of trust and authority in which the doctor acts to unburden the patient and their family of

39 Hennette-Vauchez (note 14) 377.

40 Ibid.

41 Ibid. 377–378.

42 Ibid. 378. ‘However clear the law may be in theory, French legal and medical actors have long shown reluctance to accept the logical consequence of the informed consent requirement, at least as far as the right to refuse life-prolonging medical treatment is concerned.’

43 *Garnier*, Conseil d’État, 29 July 1994

44 *Senanayake*, Cour administrative d’appel de Paris, 9 June 1998.

45 R. Horn, ‘“I don’t need my patients’ opinion to withdraw treatment”: patient preferences at the end-of-life and physician attitudes towards advance directives in England and France’ (2014) 17(3) *Medicine, Health Care, and Philosophy* 425, 425.

46 R. Horn, ‘Advance directives in English and French law: different concepts, different values, different societies’ (2014) 22(1) *Health Care Analysis* 59, 69.

47 Ibid.

48 Ibid.; B Dickenson, ‘Cross-cultural issues in European bioethics’ (1999) 913 *Bioethics* 249.

emotionally distressing healthcare decisions.⁴⁹ It is in this context that the provision of end-of-life care in France must be understood.

The tension between autonomy and medical paternalism is reflected in debates on the legalisation of euthanasia and the expansion of palliative care. Thouvenin questions whether the opposition between euthanasia and palliative care in France masks a fundamental question about who decides and how it is decided that a person whose health has significantly deteriorated can die.⁵⁰ The interplay between autonomy and paternalism therefore shapes how end-of-life decisions are made and will impact on the experience and accessibility of palliative care in practice. As it stands, the legal framework for palliative care in France reflects the evolving debate about the contours of end-of-life care.

6.2 The legal framework for palliative care

There have been several legislative milestones for palliative care in France. These laws have clarified aspects of decision-making but have also raised questions about the limits of law at the end of life. In addition to Law n° 91-748 in 1991, there is Law n° 99-477 from 1999 which guarantees a right to access palliative care, the Kouchner law of 2002, Leonetti's law of 2005, and the Claeys-Leonetti law of 2016. These can be viewed as markers of a patient–physician relationship in a state of transition. It is a relationship which alternates between defining patient rights and affirming the role of the physician.

6.3 Law n° 99-477 of 9 June 1999

Law n° 99-477 of 9 June 1999 was enacted to ensure the right to access palliative and accompanying care for any sick person whose condition so requires it.⁵¹ The concept of palliative care is defined in the legislation as the active and continuous care practiced by an interdisciplinary team in an institution or at home. The team aims to relieve pain, alleviate psychological suffering, safeguard the dignity of the sick person, and to support the patient's family and friends.⁵² This definition

49 S. Sayare, 'French Families Challenge Doctors on Wrenching End-of-Life Decisions' *New York Times* (31 July 2014).

50 D. Thouvenin, 'La loi n° 2005-370 du 22 avril 2005, dite loi Leonetti: la médicalisation de la fin de vie' in J.M. Ferry and N. Martin, *Fin(s) de vie: Le débat* (Presse Universitaires de France 2012) 308. «Déjà à cette époque, on pouvait légitimement se demander si l'opposition radicale entre soins palliatifs et euthanasie ne masquait pas *la question centrale de savoir qui décide et comment, du moment de la mort d'une personne* dans des situations où son état de santé s'est fortement dégradé: l'équipe médicale ou le patient?»

51 Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs «Art L. 1er A. – Toute personne malade dont l'état le requiert a le droit d'accéder à des soins palliatifs et à un accompagnement.»

52 Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs «Art L. 1er B. Les soins palliatifs sont des soins actifs et continus pratiqués par une équipe interdisciplinaire en institution ou à domicile. Ils visent à soulager la douleur, à apaiser

demonstrates that palliative care in France is more than physical pain management but also addresses the psychological distress experienced by the patient. Under this law hospitals and other healthcare institutions are obliged to make available appropriate pain therapy and palliative care for the patient. Additionally, the law recognises that patients may refuse further examination or treatment; a cautious recognition of the patient's right of autonomy.⁵³

The law provides for the contribution of volunteers so as to strengthen the psychological and social environment of the sick person and their family and friends.⁵⁴ Article 11 of the law addresses aspects of labour law as it sets out care-giver's leave for family members or persons living in the home. This aspect of the law has only been applied since 2010 but it demonstrates that there are many ways in which legislation can shape and ameliorate the care received at the end-of-life.⁵⁵ The European Association of Palliative Care have argued that the '[i]ntroduction of similar legislation in other countries would be a major step in the development of palliative care. Legal recognition of reimbursement claims for palliative care leave would further reduce the burden of care for family members and other carers.'⁵⁶

6.4 Law n° 2002-303 of 4 March 2002

Law n° 2002-303 of 4 March 2002 concerning patients' rights and the quality of the health system came to be known as Kouchner's law after Bernard Kouchner, Secretary of State for Health. This represented a substantial step forward for patients' rights. The law introduced new concepts relevant to healthcare decision-making but also served to reiterate the existing law in France. It was suggested that Kouchner's law was '[p]resented and enacted as a way to establish an equilibrium between the roles of doctor and patient within the therapeutic relationship.'⁵⁷ This balance is difficult to achieve and for some the increased recognition of autonomy signalled a move away from the traditional relationship of trust and respect between the patient and their physician and instead brought about a more adversarial relationship.⁵⁸

la souffrance psychique, à sauvegarder la dignité de la personne malade et à soutenir son entourage.»

53 Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs «Art L. 1er C. La personne malade peut s'opposer à toute investigation ou thérapeutique.»

54 Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs, Article 10.

55 K. van Beek and others, 'Comparison of legislation, regulations and national health strategies for palliative care in seven European countries (Results from the Europall Research Group): a descriptive study' (2013) 13 *BMC Health Services Research* 275.

56 L. Radbruch and others, 'White Paper on standards and norms for hospice and palliative care in Europe: part 2' (2010) 17(1) *European Journal of Palliative Care* 22, 26.

57 Hennette-Vauchez (note 14) 380.

58 E. Dunet-Larousse, 'La loi du 4 mars 2002 et les soins palliatifs' (2003) 2 *Médecine Palliative* 259, 266 «Enfin, il apparaît que cette loi exprime une réalité que l'on aurait

The law provided for the selection of a 'person of confidence' and resulted in changes to the confidentiality of medical records. It also addressed the proportionality of treatment, the right to treatment for pain, the right to refuse treatment, and it affirmed the patient's dignity.⁵⁹ Under Article 3 of Kouchner's law it is set out that every person has the right to receive care so as to relieve pain.⁶⁰ This is in addition to requirements established by the Law of 1999 and the Code of Medical Ethics.⁶¹ Yet, it is a general declaration with little detail on what this right actually means in practice. Dunet-Larousse highlighted that the treatment of pain requires time, training, human and material resources.⁶² On this point, Dunet-Larousse concluded that the means and will were still lacking in France.

One of the more significant aspects to emerge from Kouchner's law was the role of the patient in treatment decisions. The patient was afforded a more central role in structuring and shaping their care as illustrated by Article L1111-4 of the Public Health Code:

Every person, together with the healthcare professional and the information and recommendations which they provide, shall make decisions concerning their health.

The doctor must respect the person's will after informing him/her of the consequences of their choices. If the person's decision to refuse or interrupt treatment is life-threatening, the doctor must make every effort to convince the person to accept essential care.

No medical procedure or any treatment may be performed without the free and informed consent of the person and such consent may be withdrawn at any time.⁶³

The increased role of the patient was a clear recognition that a right to refuse to treatment exists in France. However, the equilibrium between patient and doctor is not fully clarified. Even in circumstances where the patient refuses treatment, the doctor was to make every effort to convince the person to accept essential care. It is not clear what is meant by 'every effort' and it posed a potential liability for the healthcare professional. Although this law was a step forward in certain respects it did not comprehensively resolve many of the issues in palliative and end-of-life care.

aimé ne jamais avoir à étudier, car elle montre plus une relation conflictuelle qu'un rapport de confiance et de respect.»

59 Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé, article 3.

60 Ibid. «Toute personne a le droit de recevoir des soins visant à soulager sa douleur.»

61 Hennette-Vauchez (note 14) 372. 'Since the 2002 Law on Patients' Rights, the Code has been incorporated in the *Code de la santé publique*, which is composed of both legislative and executive regulations: it is divided into a "*partie législative*" and a "*partie réglementaire*".'

62 Dunet-Larousse (note 58) 261.

63 Code de la Santé publique, Article L1111-4.

6.5 Law n° 2005-370 of 22 April 2005

Law n° 2005-370 of 22 April 2005 relating to the rights of the sick and the end of life is referred to as Leonetti's law. The law was partly motivated by the case of a young man named Vincent Humbert. Due to a road traffic accident, he was quadriplegic, blind, and mute. Vincent was assisted in writing a letter in 2002 to the President of the Republic, Jacques Chirac. The letter requested a right to access euthanasia as there was no possibility of improvement in his condition. The request was not granted and this led his mother, Marie Humbert, and physician, Dr Chaussoy, to bring about his death.⁶⁴ Marie Humbert injected Vincent with a large dose of barbiturates which put him in a coma. Dr Chaussoy subsequently injected him with potassium chloride which ended his life. Marie Humbert was charged with the 'administration of toxic substances' whereas Dr Chaussoy was charged with 'poisoning with premeditation'.⁶⁵ The case resulted in public debate on euthanasia and was notable as it directly involved a doctor and occurred in a healthcare facility. The case was eventually dismissed in 2006.

Owing to the Humbert case, the French Parliament established a working committee on end-of-life issues in 2003.⁶⁶ Cardiologist and politician, Jean Leonetti, acted as president and rapporteur of the working committee. The committee heard 81 presentations over an eight-month period from people in the humanities, health sciences, and from various religious faiths.⁶⁷ The committee visited a palliative care unit in Paris and also travelled to Belgium and the Netherlands to review the laws on euthanasia which those countries enacted.⁶⁸ The work of the committee informed the subsequent legislation, law n° 2005-370.

The law does not radically depart or alter the law which existed in France. Instead it can be suggested that the purpose of the law was to bring legislative clarity to healthcare decision-making at the end-of-life.⁶⁹ This clarity was especially

64 Dany (note 1).

65 Horn (note 9) 202.

66 R.C. Fox and J.P. Swazey, *Observing Bioethics* (Oxford University Press 2008) 246 'On October 15, 2003, at the demand of the president of the National Assembly, such a Mission of Information on "accompaniment of the end of life" was established.; A. Baumann and others, 'Ethics review: end of life legislation – the French model' (2009) 13(1) *Critical Care* 204.

67 J. Leonetti, 'Respecter la vie, Accepter la mort' Report N° 1708 fait au nom de la mission d'information sur l'accompagnement de la fin de vie 2004; Fox (note 66) 246 'Over a period of 8 months, they heard 81 invited presentations, made by historians, philosophers, sociologists, members of various health professions and health care institutions, jurists, political officials, and, in keeping with the "neutrality" of the French secular Republic in treating all religions and philosophies equally, authoritative spokespersons for Catholicism, Protestantism, Judaism, Islam, and the Masonic Lodges.'

68 Ibid.

69 Hennette-Vauchez (note 14) 383 Purpose of the law 'is to give a clear (and thus protective) legislative framework for medical decision-making at the end of life'.

significant for the healthcare professional.⁷⁰ It addressed some of the key concerns in care at the end-of-life, namely the right to refuse treatment, advance directives, the concept of medical futility, and the role of the person of confidence. Significantly, supporters of the law saw it as a way of addressing end-of-life issues without providing for the liberalisation of laws on euthanasia.⁷¹

6.5.1 The withholding and withdrawal of medical treatment

Article 1 of law n° 2005-370 set out that medical treatment must not be pursued to the point of unreasonable obstinacy. Treatment can be withheld or withdrawn in circumstances where it appears unnecessary, disproportionate or would have no other effect than the mere artificial maintenance of life. This requires doctors to weigh up the benefits and burdens of a proposed course of treatment in deciding whether treatment should be withheld or withdrawn. It reflects the concept of futility in assessing the impact of a form of healthcare. However, the concept of therapeutic obstinacy goes beyond that of futility. As Spranzi notes, ‘its meaning is wider than “medically useless” and carries both moral overtones – inappropriate because it is “unreasonable” – and a subjective and context-dependent component.’⁷² By clarifying the law on treatment withdrawal, the law underlines the proscription on acting to bring about the patient’s death.⁷³ This distinction contributed to a widening of the ‘ideological rift’ which exists between palliative care advocates and supporters of euthanasia.⁷⁴

In end-of-life decision-making there will be occasions where the patient lacks sufficient capacity to contribute to the process. These circumstances are addressed by Article 5 of Leonetti’s law which provides that when a person is not able to express his/her wishes, the limitation or cessation of treatment which could put the patient’s life in danger cannot be realised without complying with the collegial procedure defined by the Code of Medical Ethics, and without consulting the person of confidence or the family or failing that, one of his/her relatives and, where appropriate, the person’s advance directive.⁷⁵ Article 9 of Leonetti’s law is somewhat similar as it applies to individuals lacking capacity but specifically focuses

70 Ibid. 383 ‘What it really does is not so much to establish some fundamental rights of patients as to legalise a number of medical decision-making practices at the end of life that might have been thought threatened by some criminal prosecutions in recent years.’; Horn (note 45) 428.

71 Ibid. ‘presented by its promoters as a means of addressing end-of-life issues without taking the path of legalisation of euthanasia.’; Spranzi (note 14) 256 ‘By showing that the “good death practices” allowed by the law could meet all but a small minority of assisted death requests, it was also intended to quell public outcry in the face of highly publicized cases and recurrent proposals for the legalization of active euthanasia.’

72 Spranzi (note 14) 255.

73 Ibid. 256 ‘By explicitly authorizing passive euthanasia, the law implicitly reaffirms the prohibition of active euthanasia.’

74 Ibid. 257.

75 Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie, Article 5.

on patients in an advanced or terminal phase of an illness. In such circumstances, treatment can be limited or stopped when it is unnecessary or disproportionate and has no other effect than prolonging the patient's life. The decision to limit treatment also requires a collegial procedure as well as consultation with family members and the person of confidence.⁷⁶ The collegial procedure referenced in Leonetti's law allows for the independent validation of the patient's diagnosis and prognosis.⁷⁷ It serves to provide an additional layer of scrutiny thereby ensuring that treatment is not unduly limited. The collegial decision-making process does not include family members but is limited to members of the healthcare team and the opinion of a consulting doctor.⁷⁸ Family members along with the person of confidence must only be consulted. There is no requirement that their input be determinative or even that 'their representation of the patient's views are entitled to great weight'.⁷⁹ Horn described the decision-making process as unilateral rather than participative.⁸⁰ Nonetheless, in circumstances where the patient has capacity they are afforded a degree of autonomy.

6.5.2 Recognition of patient autonomy

Leonetti's law recognises the patient's autonomy as well as providing for precedent autonomy in the form of advance directives. It reiterates the right of a patient to refuse treatment and, importantly, this right applies to every treatment. Patients could therefore refuse treatment such as artificial nutrition and hydration. For instance, it is set out in Article 6 of law n° 2005-370 that:

When a person, in an advanced or terminal stage of a serious and incurable condition, for whatever reason, decides to limit or stop all treatment, the doctor respects his will having informed him of the consequences of his choice. The patient's decision is recorded in his medical file.⁸¹

The doctor safeguards the dignity of the dying person and ensures the quality of their end of life by providing the care referred to by Article L.1110-10.⁸²

76 Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie, Article 9; R. Cremer, and others, «Le consultant pour les limitations et les arrêts de traitement en réanimation» (2012) 4 *Reanimation* 231.

77 S. Chrétien and others, 'End of life, promoting the collegial procedure' (2015) 800 *Soins: la Revue de Référence Infirmière* 25.

78 Code of Public Health, Article R4127-37-2, III.

79 Hennette-Vauchez (note 14) 384.

80 Horn (note 46) 67 'It appear then that the French model is what I will call here unilateral, that is, one-sided, rather than participative.'

81 Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie, Article 6 «Lorsqu'une personne, en phase avancée ou terminale d'une affection grave et incurable, quelle qu'en soit la cause, décide de limiter ou d'arrêter tout traitement, le médecin respecte sa volonté après l'avoir informée des conséquences de son choix. La décision du malade est inscrite dans son dossier médical.»

82 Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie, Article 6 «Le médecin sauvegarde la dignité du mourant et assure la qualité de sa fin de vie en dispensant les soins visés à l'article L. 1110-10.»

The patient's decision should be constant and reiterated within a reasonable period of time.⁸³ The purpose of this is to satisfy the medical team that the patient is definite about the nature of their decision.⁸⁴ The above quote also references dignity which is a recurring theme in end-of-life care and in Leonetti's law. As was noted in Chapter 3, there is often a distinct lack of clarity about what exactly dignity means in practice. There is a considerable subjective element as to what dignity entails and it is necessary to understand the will and preferences of the patient but this is not always achieved. Baumann noted that '[i]n the absence of a patient's will being clearly recorded, the risk of unsuitable or blurred decisions that lengthen the duration of the dying process is deemed to increase.'⁸⁵ In this respect, Leonetti's law was the first legislation in France to provide for advance directives.

Leonetti's law allows every person who has reached the age of majority to draw up an advance directive in case they are ever unable to express their wishes. The advance directive serves to indicate the wishes of the person concerning their end of life and the conditions for the limiting or cessation of treatment. The law established a time limit on the applicability of such advance directives. If the advance directive was made less than three years before the patient lost consciousness then the doctor is to take it into account for any examination, intervention, or treatment. This reflects possible changes in the law, changes in personal circumstances, and advancements in medical technology. No reason is provided why the specific time limit of three years was selected.⁸⁶

The law suggests that while the advance decision could be taken into account there was no obligation for the doctor to respect such a decision. Hennette-Vauchez described the situation as follows, 'the law does not go much beyond acknowledging that when such directives exist they may be used as information concerning the will of an incompetent patient.'⁸⁷ The law is therefore not a significant step forward for precedent autonomy as it provides a narrow scope of applicability. Moreover, it appears that the introduction of advance directives was not based on a desire to enhance patient autonomy but were a way to 'ease doctors' feelings of guilt' around treatment withdrawal decisions.⁸⁸ The status and rationale for advance directives reflects the emphasis placed on legal clarity for doctors and the comparably poor status of patient self-determination in France at this point.⁸⁹

The views and wishes of the patient can also be represented through consultation with the person of confidence but this does not carry considerable weight.

83 Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie, Article 4.

84 Baumann (note 66) [4].

85 Ibid. [2].

86 Horn (note 46) 64.

87 Hennette-Vauchez (note 14) 383.

88 Horn (note 45) 431.

89 Horn (note 46) 64 'The fact that ADs have no obligatory value indicates the relatively weak position of patient self-determination in regard to treatment refusal in French law'.

The person of confidence was created by the law of 2002. In the 2005 law it is set out that where a person who is in an advanced or terminal condition of a serious and incurable illness, has designated a person of confidence, the latter's opinion, except in urgent or impossible situations, shall take precedence over other non-medical opinions, excluding advance directives, in decisions for examination, intervention, or treatment taken by the doctor. There is very little room for the patient's voice to be heard in these circumstances. The person of confidence serves to represent the views of the patient but does not act as a surrogate decision-maker. The responsibility for healthcare decisions rests with the doctor treating the patient. Baumann described the person of confidence as 'a witness who reports a patient's point of view and wishes regarding their end of life if the patient is unable to do so'.⁹⁰ Consequently, while the law suggests an increase in patient autonomy the reality is that healthcare professionals still control the decision-making process.⁹¹

6.5.3 Double effect reasoning

Article 2 of Leonetti's law suggests a recognition of the concept of double effect in circumstances where pain relief is being administered. It is set out that if the doctor cannot relieve the suffering of a person in an advanced or terminal stage of a serious and incurable illness, whatever the cause, by applying a treatment which may have a secondary effect of shortening the patient's life, he must inform the patient, the person of confidence, the family, or relatives. This would suggest that the law allows for palliative sedation although it does not expressly mention the practice.⁹² Delbeke cited this part of Leonetti's law as an example of how legislation could explicitly provide a justification in law which would negate suggestions of palliative sedation being a criminal act.⁹³ Regardless, it appears that there was a degree of confusion amongst doctors as to where the limits of treatment lie in this area. This was highlighted by Horn who recognised that for some doctors in France 'their wish to relieve pain is inhibited by their fear of employing strong painkillers, which might risk producing respiratory depression. Most of the physicians equated this so called secondary effect with euthanasia'.⁹⁴ Greater steps would therefore be required to alter this perception.

90 Baumann (note 66) [4].

91 Spranzi (note 14) 256.

92 K. Raus and others, 'Controversies surrounding continuous deep sedation at the end of life: the parliamentary and societal debates in France' (2016) 17 BMC Medical Ethics 36 'It has been suggested that the Loi Leonetti also allows continuous deep sedation as a form of far-reaching symptom control, although it does not mention the practice.'

93 E. Delbeke, 'The legal permissibility of continuous deep sedation at the end of life: a comparison of laws and a proposal' in S. Sterckx and others (eds) *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 136.

94 Horn (note 9) 203.

6.5.4 Developing palliative care capacity

Articles 11, 12, 13, 14, and 15 of Leonetti's law make specific reference to palliative care. These articles do not address practices in palliative care but refer to training, the identification of palliative care beds, and capacity building for palliative care in France. The law provides for the expansion of palliative care and establishes a legislative framework for achieving this. Leonetti's law therefore supports the expansion of palliative care provision both in existing facilities, and in medico-social institutions which provide elder care, and locations where long-term healthcare is provided.

6.6 Decision-making in practice: pre- and post-Leonetti

Prior to the introduction of Leonetti's law, as well as Law n° 99-477 and Kouchner's law, a study on the withholding and withdrawal of treatment in intensive care units was conducted by Ferrand et al.⁹⁵ The study examined the treatment decisions for patients who were admitted to participating intensive care units in the period of 1 February 1997 to 31 March 1997. Among the findings of the study was that 53% of deaths in the intensive care units 'were preceded by a decision to limit life-supporting therapies'.⁹⁶ The reason for limiting treatment was most often based on futility or low expected quality of life. The decision to withhold or withdraw treatment was made by a single doctor in 12% of cases, by all ICU medical staff in 54%, and without nursing staff in 34% of cases.⁹⁷ Nurses often have regular close contact with the patient and should be involved in these types of decisions as much as possible.⁹⁸ In 44% of cases the family was informed and involved in making the decision while they were simply notified about a decision in 13% of cases. The study demonstrated poor recognition of autonomy as the patient was seldom involved in the decision-making process. In 8% of cases the patient's willingness to limit their own care was known, while only 0.5% of patients were involved in the decision to withhold or withdraw treatment. A caveat for this study is that as it was based on ICU patients it would be expected that many of these people were experiencing significant health problems which resulted in diminished capacity. 27% of the patients were assessed as being sufficiently competent to be informed of the decisions.⁹⁹ As this study was prior to the legislative changes in France it would therefore be expected that the approach to decision-making would have shifted over the years towards greater patient participation.

95 E. Ferrand, and others, 'Withholding and withdrawal of life support in intensive-care units in France: a prospective survey' (2001) 357(9249) *Lancet* 9.

96 Ibid.

97 Ibid.

98 For contrast see J.S. Turner and others, 'Limitation of life support: Frequency and practice in a London and a Cape Town intensive care unit' (1996) 22 *Intensive Care Medicine* 1020.

99 Ferrand (note 95) 12.

In early 2013 a study on the withholding and withdrawal of treatment in French ICUs was conducted by Lesieur et al.¹⁰⁰ During the study period, 1132 patients died in participating ICUs. 52% of deceased patients went through a formalised decision-making process before death. In 23% of cases the wishes of the patient were known and were expressed in several ways. The patient's wishes were 'spontaneously voiced' in 9.4% of cases, 1.3% through advance directives, 1.3% through the person of confidence, and 13.9% through family or relatives.¹⁰¹ The views and wishes of the patient were therefore unknown in over three quarters of cases. The lack of insight into the patient's preferences meant that decisions were principally based on medical judgement.¹⁰² According to Leonetti's law such decisions are to involve a collegial procedure. This is an important control in the formal decision-making framework under Leonetti's law yet an external consultant doctor was involved in only 46% of decisions.¹⁰³ This suggests that the decision-making framework was not being fully implemented.¹⁰⁴ In any case, there are considerable similarities between the findings of Ferrand et al. and the Lesieur et al. study. This led Lesieur et al. to state that 'one could argue that the law provided a legal framework for practices that already existed informally.'¹⁰⁵ While Leonetti's law clarified the legality of end-of-life decision-making for healthcare professionals it did not have an appreciable impact on patient autonomy in practice.

Awareness and familiarity with Leonetti's law was examined in a study conducted by Robert et al.¹⁰⁶ This study surveyed members of the French Intensive Care Society about end-of-life practices in the ICU. There was a total of 616 respondents to the survey. 82.5% of respondents reported having a good knowledge of Leonetti's law and 88% said they often applied the law. This does not fully reflect the findings of the Lesieur et al. study, particularly in relation to the collegial procedure, although, this procedure was identified as the most common difficulty in applying the law.¹⁰⁷ The context for this study also sought to capture the proportion of healthcare professionals who would support the administration

100 O. Lesieur and others, 'Withholding or withdrawal of treatment under French rules: a study performed in 43 intensive care units' (2015) 5 *Annals of Intensive Care* 15. 'The study period (60 or 90 consecutive days in normal operating conditions) took place during the first half of 2013. All patients admitted to the ICU who underwent a WhWd procedure according to the terms of the French Leonetti law were enrolled in the survey.'

101 Ibid. 15.

102 Ibid. 'Because patients' preferences were unknown in more than three quarters of cases, decisions remained primarily based on medical judgment.'

103 Ibid. 17 'An external consultant physician was involved in the decision-making process in less than half of the 777 cases (356 patients, 46 %): 142/344 (41.3 %) and 214/433 (49.4 %) cases for Wh and Wd, respectively (p < 0.05).'

104 Ibid. 22 'Because many hospitals only have one ICU, referring to an independent and relevant arbitration may be challenging.'

105 Ibid. 21.

106 R. Robert and others, 'End of life in the intensive care unit: should French law be adapted?' (2014) 4(6) *Annals of Intensive Care* 6.

107 Ibid. 7.

of lethal drugs and their reasons for doing so. This was motivated by media coverage, a law on medically assisted dying and access to palliative care which was tabled in Parliament on 8 June 2012, and the report on end-of-life practices prepared by Professor Sicard.¹⁰⁸ On condition that appropriate palliative care is administered, 25.7% supported a law permitting euthanasia in intensive care while 26.5% opposed such a law. The question was formulated in several ways and resulted in considerable divergence based on the specificity of the question.¹⁰⁹ Robert et al. recognised that '[v]arious factors can influence the wish to speed the death of a patient in order to shorten his or her suffering. One that is certainly crucial is the dividing line between the administration of lethal drugs and the use of terminal sedation'.¹¹⁰ This dividing line was described as 'fuzzy' by Robert et al. and reference was made to concerns in the literature about the nature of intention in administering sedation.¹¹¹

Overall, Leonetti's law clarified the legality of certain practices at the end-of-life but it did not quell calls for a change in the law which would allow for the administration of lethal drugs. The debate on the limits of law at the end of life developed to the point where it could be said to reflect 'a more comprehensive view of what dying, autonomy, and dignity mean according to opposing anthropological, social, and normative perspectives'.¹¹² This debate was taken up in the 2012 presidential election and resulted in the Sicard report and the subsequent enactment of the Claeys-Leonetti law.

6.7 Law n° 2016-87 of 2 February 2016

In 2012, François Hollande's election manifesto proposed that any person in an advanced or terminal stage of an incurable illness, causing unbearable physical or psychological suffering, which cannot be relieved, may request under precise and strict conditions, to benefit from medical assistance to end their life in dignity.¹¹³ Media outlets interpreted this as a categorical statement that the law on euthanasia in France would be amended.¹¹⁴ However, after the election of President François

108 D. Sicard, 'Penser solidairement la fin de vie – Commission de réflexion sur la fin de vie en France' (Décembre 2012).

109 Robert (note 106) 9 'when couched in general terms 47% of respondents agreed with the idea of such a law, compared with 10% when the question was formulated in the more concrete terms of a clinical situation with alternatives.'

110 Ibid.

111 Ibid. 10.

112 Spranzi (note 14).

113 F. Hollande, 'Le Changement c'est Maintenant: Mes 60 Engagements pour la France' 18. Campaign pledge 21 «Je proposerai que toute personne majeure en phase avancée ou terminale d'une maladie incurable, provoquant une souffrance physique ou psychique insupportable, et qui ne peut être apaisée, puisse demander, dans des conditions précises et strictes, à bénéficier d'une assistance médicalisée pour terminer sa vie dans la dignité.»

114 France 24, 'France opens the door to medically-assisted suicide' *France 24* (Paris, 26 June 2014) <<http://www.france24.com/en/20121219-france-medically-assisted-sui>

Hollande there was a protracted period of consultation on how the proposed reform was to be accomplished. The first step in the process was the appointment of Didier Sicard, former president of the National Consultative Ethics Committee, to examine and issue a report on the law on end-of-life care in France.

6.7.1 Penser solidairement la fin de vie

The report published by the Sicard Committee was titled ‘Penser solidairement la fin de vie’.¹¹⁵ The central recommendation set out in the report was that the greatest importance should be given to the words and wishes of people at the end of life and to ensure that they are heard in their vulnerable situation.¹¹⁶ Greater respect for autonomy has been suggested in several laws but achievement in practice has proved challenging. This was demonstrated by Leonetti’s law which illustrated the disconnect between autonomy and the role of the healthcare professional. The Sicard report described it as unacceptable that Leonetti’s law was not always applied and called for a major effort to be made which would encourage adherence to the law by society along with doctors and other healthcare professionals. In addition, it was suggested that steps should be taken to ensure the effectiveness of the 1999 law, Kouchner’s law, and Leonetti’s law.¹¹⁷

The report issued recommendations on advance directives, training and education, the role of hospitals and medico-social facilities, care in the home, accompaniment, neonatology, and decisions to hasten the patient’s death when treatment is withheld or withdrawn. This last point is notable, not only for the language used, but also for comments on Leonetti’s law. It is set out in the report that when a person who is at the end of life, or by way of an advance directive, requests the stopping of all life-prolonging treatment including nutrition and hydration, it would be cruel to ‘let him die’ or ‘let him live’, without offering the possibility of an action by the doctor which would hasten the patient’s death.¹¹⁸ In the eyes of the committee such a practice could correspond with the actual

cide-euthanasia-healthcare-reform-hollande> (accessed 4 September 2017); K. Willsher, ‘Suicide of elderly French couple stirs euthanasia debate’ *The Guardian* (London, 25 November 2013) <<https://www.theguardian.com/world/2013/nov/25/suicide-elderly-couple-france-paris-euthanasia-debate>> (accessed 4 September 2017); B. Love, and E. Pineau, ‘France’s Hollande targets rich in tax-rise manifesto’ *Reuters* (26 January 2012) <<http://www.reuters.com/article/france-hollande-idINDEE80P0BI20120126>> (accessed 4 September 2017).

115 Presented to the President on 18 December 2012.

116 Sicard (note 108) 95.

117 Ibid. 96. «Pour assurer l’effectivité des textes de loi (loi relative à l’accès aux soins palliatifs 1999, loi Kouchner 2002, loi Leonetti 2005), prendre des dispositions réglementaires concernant: les conditions de la délivrance d’une information précise, compréhensible, Claire et appropriée au malade et à ses proches, sur la proposition d’abstention, de limitation ou d’arrêt de traitements, ou d’intensification du traitement de la douleur et des symptômes, ou de sédation terminale; les conditions du respect de la volonté de la personne; les conditions de la traçabilité des procédures retenues.»

118 Ibid. 99.

circumstances of deep sedation as set out in Leonetti's law.¹¹⁹ While Leonetti's law made reference to the principle of double effect it is doubtful that it sought to provide for situations where death was deliberately hastened. Instead, it may be the spirit of the law to which the committee appealed.¹²⁰ At any rate, the Sicard report suggests that such a decision should be based on good practice guidelines rather than a new legislative provision.

On the issue of assisted suicide, the Sicard report recognises the possible motivations behind such a request and sets out elements which should be considered by legislators should they decide to legislate for the practice. Nevertheless, the report affirms that assisted suicide is not a solution to address the absence of palliative care and accompaniment. An unequivocal position is adopted on euthanasia as the report suggests that any legislation on this would represent a fundamental societal shift and it effectively condemns the practice.

There are two main observations contained in the conclusion to the Sicard report. First, there has been insufficient application of the laws addressing palliative care in France. This includes the law guaranteeing access to palliative care, Kouchner's law, and Leonetti's law.¹²¹ Second, it is noted that there are particularly dramatic inequalities at the end of life.¹²² Steps must therefore be taken to ensure that law fully contributes to lessening these inequalities while being cognisant of its inherent limitations. In sum, the Sicard report represents a significant first step in the legislative process as it acknowledged the weakness of previous laws and highlighted areas in need of reform.

Subsequent consultation took place with the National Consultative Ethics Committee. At the time of the first consultation it was relatively clear that any new law would seek to complement and improve on Leonetti's law.¹²³ The second opinion issued by the National Consultative Ethics Committee called for the further development of palliative care, greater respect for advance directives, a greater understanding of patients' wishes, and, significantly, a right to palliative sedation.¹²⁴ It was the right to palliative sedation which provided the focal point for new legislation.

6.7.2 Substance of the Claeys-Leonetti Law

Alain Claeys and Jean Leonetti introduced the law titled 'creating new rights for the sick and those at the end of life'. The law aimed to deliver on the campaign

119 Ibid. 100.

120 Ibid.

121 Ibid. 103 «l'application insuffisante depuis treize ans de la loi visant à garantir l'accès aux soins palliatifs, depuis dix ans de la loi relative aux droits des malades (loi Kouchner), et enfin, depuis sept ans, de la loi Leonetti.»

122 Ibid. «le caractère particulièrement dramatique des inégalités au moment de la fin de vie.»

123 L. Clavreul, «Le Comité d'éthique divisé sur l'aide à mourir» *Le Monde* (1 July 2013).

124 Comité Consultatif National d'Éthique, «Rapport du CCNE sur le débat public concernant la fin de vie» (21 octobre 2014); L. Clavreul, «Fin de vie: la volonté et les droits des patients doivent être mieux pris en compte» *Le Monde* (23 October 2014).

pledge of François Hollande while placating those with opposing viewpoints on end-of-life issues. This attempt at compromise has been problematic as it did not represent the conclusive step forward which ‘right to die’ campaigners had hoped for and it does not seem to have comprehensively defended the status quo.¹²⁵ The Association for the Right to Die with Dignity described the text of the law as the ‘fruit of a soft consensus’, while Phillippe Bataille suggested that it would ‘encourage a preposterous practice of euthanasia’.¹²⁶ The law reinforces many existing patient rights but also introduces new rights at the end of life; the most significant of which relates to the provision of continuous deep sedation. The law also brought about changes to advance directives as well as defining artificial nutrition and hydration as medical treatment.

Concerns about central aspects of the law are evident from the legislative process and debates in the National Assembly and the Senate. The Bill passed in the National Assembly on 17 March 2015.¹²⁷ However, it was rejected by the Senate on 23 June with 196 votes against and 87 votes for. Several amendments to the law were proposed in the Senate during this time. One of the amendments sought to categorise artificial hydration as care which could be continued until the death of the patient. The second amendment sought to move the bill away from the narrow focus on continuous deep sedation to instead address all forms of deep sedation. These amendments were not subsequently implemented by the National Assembly which again passed the Bill before returning it to the Senate. On this occasion, the Senate approved the Bill.¹²⁸ This was followed by a mixed commission which made further amendments before the text became law on 27 January 2016.

The discussion of this law will be guided by the same headings used for the Netherlands in Chapter 5, namely, defining the practice of palliative sedation, the indications and preconditions for sedation, the decision-making process, the administration of fluids, and the administration of palliative sedation. Reference will also be made to the Code of Medical Ethics along with the guidelines which have been issued by the SFAP. In discussing this law, a central concern is whether it effectively clarifies the legality of continuous deep sedation. This section also

125 F. Béguin, «La loi Claeys-Leonetti sur la fin de vie définitivement adoptée» *Le Monde* (Paris, 27 January 2016) <http://www.lemonde.fr/societe/article/2016/01/27/fin-de-vie-ce-que-va-changer-la-nouvelle-loi-claeys-leonetti_4854266_3224.html> (accessed 4 September 2017).

126 Ibid.

127 (–), «La loi sur la fin de vie votée à l'Assemblée» *Le Monde* (Paris, 17 March 2015) <http://www.lemonde.fr/fin-de-vie/article/2015/03/17/l-assemblee-vote-aujourd-hui-la-loi-sur-la-fin-de-vie_4595401_1655257.html> (accessed 4 September 2017). Vote in the National Assembly with 436 votes in favour, 34 votes against, and 83 abstentions.

128 Raus (note 92) [3] ‘this time the Senate approved the bill with a significant majority (10 votes against and 287 in favour), after which the proposal was, in a final stage, discussed in a mixed commission consisting of members of the Assemblée and the French Senate.’; A. Gulland, ‘French parliament passes law to allow sedation at end of life’ (2016) *British Medical Journal* 352.

seeks to draw out the broader implications of the law for palliative care in practice. It will be argued that the law places a disproportionate responsibility on the patient for changing the standard of palliative care, particularly as the application of the law must overcome the autonomy–paternalism divide in the French healthcare system. Additionally, it is argued that this law narrows the perceived distance between euthanasia and specialist palliative care. The Sicard report set out that a practice such as assisted suicide is not a solution to address the absence of palliative care and accompaniment; the reverse is also true.

6.7.3 Defining the practice of continuous deep sedation: a practice beyond palliative medicine?

In Article 3 of the Claeys-Leonetti law it is set out that:

Upon the request of the patient to avoid all pain and not to undergo unreasonable obstinacy, deep and prolonged sedation bringing about an altered state of consciousness to be continued until death and combined with analgesia and the ending of all life-support systems, shall be implemented in the following cases...¹²⁹

The sedation results in an altered state of consciousness and is maintained until the patient dies. However, the categorisation of the practice is to be questioned. While the Dutch guideline sought to define palliative sedation as normal medical practice this is not the approach which has been adopted in France. For instance, it has led Raus et al. to raise the question of whether such a form of sedation is a *sui generis* practice.¹³⁰

Article 3 of Claeys-Leonetti has predominantly been interpreted as establishing a right to continuous deep sedation. This suggests a practice which is beyond symptom control as set out in Leonetti's law but does not constitute euthanasia.¹³¹ It would be outside the bounds of traditional palliative medicine and a strong argument could be made that it is therefore a *sui generis* practice. However, Article 3 could also be viewed as establishing a right to request continuous sedation. There are requisite indications and preconditions which must be satisfied if continuous sedation is to be administered. The process is also subject to collegial decision-making and oversight. A patient can therefore request continuous deep sedation but if the indications are not present then sedation will not be administered. It can be suggested that it is an explicit recognition of a positive obligation arising from the

129 Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie, article 3.

130 Raus (note 92).

131 Ibid. [3]–[4] 'By discussing a possible legislative framework specifically pertaining to continuous deep sedation, French politicians are suggesting that continuous deep sedation is a practice that is clearly and relevantly different from both symptom control (which was already regulated by the Loi Leonetti) and euthanasia or physician-assisted suicide (which remain illegal in France).'

patient's right of autonomy. While the patient can make such a request, it will not be determinative.

There is, however, a duty for healthcare professionals to provide appropriate pain relief under Article 1 of Claeys-Leonetti. This article states that '[e]very person has the right to a dignified end of life and to be accompanied with the best possible pain relief. Health professionals are to implement all available means for this right to be respected.'¹³² This would include the provision of continuous deep sedation. Prior to this law, it was already established in the Public Health Code that any sick person whose condition so requires it is entitled to access palliative care.¹³³ Healthcare professionals already had a responsibility to address pain, and patients had a right to access palliative care. It would appear that it is not a *sui generis* practice under the law. In contrast, it is the manifestation of the demand for greater autonomy and control at the end-of-life. It represents an inordinate political gesture which adds further confusion to the law in this area. This also highlights a critical deficiency in the law. In order to exercise the right to request continuous deep sedation, the patient must be aware that such a right exists, thereby placing the burden on the patient. As such, it is likely that the prospect of sedation is first raised by the healthcare professional and not the patient in a vulnerable condition.

6.7.4 Indications and preconditions for continuous deep sedation

The indications and preconditions for sedation are set out in Article 3 of the Claeys-Leonetti law. Continuous deep sedation can be implemented in cases where:

- 1°...the patient suffers from a serious and incurable condition which is life-threatening in the short term and presents suffering which is refractory
- 2° When the decision of a patient suffering from a serious and incurable condition to stop treatment has life-threatening consequences in the short term and could lead to unbearable pain.¹³⁴

There are two points which must be drawn out in more detail, namely what is meant by the 'short term' and what constitutes a refractory symptom. These are not clarified in the law and the Code of Medical Ethics provides no additional instruction. To understand how these terms are to be interpreted, assessed, and applied in practice it is necessary to consult SFAP guidance on the nature of refractory suffering. This guidance was issued after the Claeys-Leonetti law and

132 Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie, article 1.

133 Code of Public Health, Article L1110-9.

134 Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie, article 3; See SFAP translation of Loi n° 2016-87, <http://www.sfap.org/system/files/resume_anglais_loi_clayes_leonetti.pdf> (accessed 4 September 2017).

serves to inform and support healthcare professionals by clarifying aspects of medical practice in the context of the new law. The SFAP guidance however is not binding.

The guidance defines suffering as refractory if all ways of treatment and available accompaniment have been proposed and/or implemented without obtaining relief for the patient, or cause unacceptable adverse effects or that their therapeutic effects are unlikely to occur within an acceptable timeframe.¹³⁵ As noted in the previous chapter, determining whether suffering is refractory is largely subjective. The patient is the only person who can fully appreciate the nature of suffering, delay, and undesirable effects. The nature of the refractory symptom has been shown in previous chapters to be particularly significant for the conditions under which continuous deep sedation may be viewed as permissible. On this point, there is no distinction made in the Claeys-Leonetti law between somatic and non-somatic causes of suffering as discussed below.

Sedation for existential suffering

The SFAP guidance sets out that the evaluation of the refractory character of suffering is multidimensional. It includes physical, psychological, social, familial, existential, and spiritual elements. The evaluation is therefore multidisciplinary which requires the implementation of the collegial procedure.¹³⁶ As part of the collegial procedure it is necessary to take account of the clinical and therapeutic approaches which have been proposed or implemented. Additionally, the procedure is to take account of the possible restoration of what is described in the guidance as landmarks, namely dignity and a sense of meaning.

The psychological causes of an illness are recognised, as the evaluation of end-of-life suffering involves a careful assessment of the emotional and cognitive state, as well as the psychosocial dynamics and the therapeutic relationship. The multidisciplinary assessment is to involve a mental healthcare professional trained in the specificities of the end of life. This is essential in cases of psychological suffering and recommended for other forms of suffering due to the potential connection of symptoms.¹³⁷ The SFAP guidance recognises the difficulties posed by existential suffering and suggests that intermittent sedation could be used in circumstances where the refractory nature of psychological or existential suffering cannot be affirmed. However, the law leaves open the possibility of administering continuous deep sedation in circumstances where the patient is experiencing existential distress but no other refractory symptoms near the end-of-life. This poses a problem in defining the boundaries, both medical and legal, for this practice in France.

135 Société Française d'Accompagnement et de Soins Palliatifs, 'Évaluation du caractère réfractaire de la souffrance' (SFAP, May 2017) 4.

136 Ibid.

137 Ibid. 5.

Requisite prognosis for continuous deep sedation

The serious and incurable condition must be life-threatening in the short-term. There is no definitive period of time established in the Claeys-Leonetti law or in the Code of Medical Ethics.¹³⁸ Nonetheless, it would seem that it is a prognosis ranging from several hours to several days.¹³⁹ The SFAP have published guidance on the evaluation of the patient's prognosis for the purpose of administering palliative sedation. The previous chapter highlighted many of the issues facing healthcare professionals in determining whether continuous deep sedation could be administered. These points also arise in the SFAP guidance and results in an emphasis on the need for a multidisciplinary analysis of the patient's prognosis. It is suggested that greater medical input can assist in improving the accuracy of the prognosis.

In circumstances where a patient is experiencing refractory suffering but the prognosis is not satisfied then the SFAP guidance suggests the administration of intermittent sedation with a subsequent re-evaluation.

The SFAP guidance is informative for healthcare professionals but is not a substitute for clarity in the law. The KNMG Guideline in the Netherlands established a prognosis of two weeks to avoid life shortening effects of sedation when combined with the withdrawal or withholding of artificial nutrition and hydration. The establishment of a defined prognosis is not a guarantee that treatment will not hasten a patient's death but it establishes a minimum threshold for the administration of sedation. The Claeys-Leonetti law still leaves much to be defined by professional organisations. It touches on contentious aspects of practice without fully unpacking the normative concerns.

Deciding to stop treatment

The second indication for the administration of continuous deep sedation is that a patient who is suffering from a serious and incurable condition decides to stop treatment and this would have life-threatening consequences in the short term and could lead to unbearable pain. This has the effect of suggesting that a patient could act to bring about the conditions whereby continuous deep sedation would be administered. Consequently, a patient who refuses treatment could actively request the administration of continuous deep sedation.¹⁴⁰ The law does not state that the patient is suffering from unbearable pain but that the stopping of treatment could lead to unbearable pain. This allows for a much broader application of

138 A. de Nonneville and others, 'End-of-Life Practices in France under the Claeys-Leonetti Law: Report of Three Cases in the Oncology Unit' (2016) 9(3) *Case Reports in Oncology* 650, 653 'This raises the question of the exact definition of "short-term poor prognosis", which is not clearly specified by the law.'

139 Société Française d'Accompagnement et de Soins Palliatifs, 'Evaluation du Pronostic vital engagé à court terme' (SFAP, May 2017) 1.

140 Raus (note 92) [3].

continuous deep sedation. It would be addressing potential pain rather than actual pain. The inescapable point is that applying sedation in such a manner would bring it much more in line with euthanasia. It introduces greater uncertainty as to where the limits of treatment and the limits of law lie. In the Netherlands there are clear due care criteria which must be satisfied by the healthcare professional while the safeguard in France is the collegial procedure for decision-making; a procedure which was not always applied under Leonetti's law.¹⁴¹

The concept of unreasonable obstinacy is also a relevant indication for continuous deep sedation. In circumstances where a healthcare professional stops life-prolonging treatment on the basis of unreasonable obstinacy then continuous deep sedation can be applied.¹⁴² Raus et al. commented that 'the fact that the French proposal states that refractoriness can be also judged in patients unable to express their wish, suggests that the proposal sees the patient's voice as non-essential in determining refractoriness',¹⁴³ although, if the patient has indicated in an advance decision that he/she is opposed to the administration of continuous deep sedation, this is to be respected. While the law attempts to underline the status of patient autonomy it also signals a shift in healthcare decision-making to a point whereby more multidisciplinary decisions are to be made.

6.7.5 The decision-making process for continuous deep sedation

The Claeys-Leonetti law, the Code of Medical Ethics, and the SFAP guidance all underline the importance of the collegial procedure for decision-making.¹⁴⁴ The catalyst for this procedure may be the patient's informed request for continuous deep sedation. For instance, in Article 3 it is described as allowing the medical team to ascertain whether the indications and preconditions have been satisfied. It is therefore an important safeguard in medical practice. If the patient does not have sufficient capacity and has not provided for an advance directive then Article 37-3 of the Code of Medical Ethics requires the responsible doctor to collect information from the person of confidence, the patient's family, or close friend of the patient to determine what their wishes would be.

The motive for administering continuous deep sedation must be set out. This is also provided for in Article 37-3 of the Code of Medical Ethics. This requires that the wish set out in the advance directive or the input of the person of confidence,

141 Lesieur (note 100).

142 Code of Public Health, Article R4127-37.

143 Raus (note 92) [7].

144 The importance of the decision-making process has been underlined by J. Mazoyer and others, 'French laypeople's and health professionals' views on the acceptability of terminal sedation' (2016) 42 *Journal of Medical Ethics* 627. 'Laypeople and health professionals do not appear to be systematically opposed to TS. The most important factors in increasing its acceptability were the patients' request for sedation and the collective character of the decision-making process.'

family, or friends, in addition to the opinions gathered and motivations behind the decision are to be included in the patient's medical records.¹⁴⁵ There is no information set out about the intention of the healthcare professional in administering sedation. Article 28 of the Code of Medical Ethics sets out that the physician cannot hasten the death of a patient although it is clear that a life shortening effect can be foreseen, as was provided for in Leonetti's law.

The Code of Medical Ethics sets out that the person of confidence, family, or close friends of the patient are to be informed of the reasons for the use of continuous deep sedation and necessary support is to be provided to these people. This approach in caring for the patient's family reflects the goals of palliative care as defined by the WHO.

A requirement to consult a palliative specialist?

The Claeys-Leonetti law requires compliance with the collegial procedure for healthcare decision-making.¹⁴⁶ As noted earlier in this chapter, this process is limited to members of the healthcare team and the opinion of a consulting doctor. As it was only in 2008 that a Diploma of Complementary Specialised Studies in Pain Medicine and Palliative Medicine was introduced in France there is no explicit obligation for the independent doctor to have completed such a course. There are challenges in complying with the collegial decision-making procedure. For instance, if sedation is administered in an ICU then it is unlikely that an independent doctor would be available. Moreover, it was noted by Huxtable and Horn that 'collaboration between French hospital services and palliative care advisory teams is not always harmonious ... which raises questions about the willingness of doctors from "curative" services to consult with palliative care specialists before employing sedative medication.'¹⁴⁷

The SFAP guidance on refractory suffering set out that to ensure that all therapeutic options have been considered, the medical team should be connected with a referral team trained in palliative care.¹⁴⁸ Such expertise should be in place as a result of the national palliative care plan. In addition to such support, the input of a consultant is advised but not required by law or by the Code of Medical Ethics. The SFAP guidance suggests the input of any of the following may be necessary: a pain specialist, an anaesthetist, a psychiatrist, oncologist, or a nurse pain expert.

145 Conseil national de l'Ordre des médecins, 'Code de Déontologie Médicale' (avril 2017), article 37-3; A. Alpers, 'Criminal act or palliative care? Prosecutions involving the care of the dying' (1998) *Journal of Law, Medicine and Ethics* 308.

146 Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie, article 3.

147 R. Huxtable and R. Horn, 'Continuous deep sedation at the end of life: balancing benefits and harms in England, Germany and France' in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 165.

148 SFAP (note 135) 5.

6.7.6 The administration of artificial nutrition and hydration

The decision to withdraw or withhold ANH was carefully structured under the KNMG Guideline for Palliative Sedation. The order of and distinction between decisions was seen as essential in supporting the claim for normal medical practice and thereby the legal justification of sedation. In contrast, the approach taken in France suggests there is to be automatic cessation of life-sustaining treatment once the decision to administer sedation has been made. The Claeys-Leonetti law raises several issues including the categorisation of ANH, the basis of the treatment withdrawal decision, and limits on the role of the healthcare professional.

Article 2 of the Claeys-Leonetti law sets out that ANH constitutes treatment. This categorisation was discussed in Chapter 2 and in subsequent chapters it was shown that this categorisation was followed in England, Ireland, and the Netherlands. However, the issue does not appear to be fully settled in France. As noted above, the Senate sought to categorise ANH as care rather than treatment during the legislative process. The case of Vincent Lambert in 2015 illustrated disagreement among family members over the appropriate classification of ANH.¹⁴⁹ In a small study conducted by Boulanger et al., 57.5% of respondents believed that ANH should be categorised as care rather than treatment. In addition, 82.5% of respondents supported the right to continuous deep sedation for patients with refractory pain.¹⁵⁰ This figure is not as high as might be assumed given that the 40 respondents were patients in two palliative care institutions in France.¹⁵¹ Moreover, the SFAP proposed a limited interpretation which would classify ANH as treatment only in the context of Article 3.¹⁵² This would be a slightly strained logic in interpreting the law but the more serious issue is the basis for the limitation of ANH rather than the classification.

Under Article 3 of the law it is arguable that a single decision is made to administer sedation and limit life-sustaining treatment such as ANH. The nuanced process of the KNMG Guideline is not present in France. Instead, this form of decision-making process raises particular ethical challenges as has previously been outlined by Holm.¹⁵³ However, it also raises a significant legal challenge as it is

149 *Lambert and Others v France* App 46043/14, (ECHR, 25 June 2015).

150 A. Boulanger and others, 'Opinions about the new law on end-of-life issues in a sample of French patients receiving palliative care' (2017) 16 *BMC Palliative Care* 7.

151 Ibid.

152 Société Française d'Accompagnement et de Soins Palliatifs, «Avis 029 du 10 mars 2016 du Comité Scientifique de la SFAP Concernant la loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie» 4 «Ce point est majeur puisqu'il dit que ce n'est que « conformément à l'alinéa précédent » et donc que dans cette situation-là, que la nutrition et l'hydratation sont des traitements et peuvent être arrêtés au même titre que les autres après réunion collégiale.»

153 S. Holm, 'Terminal sedation and euthanasia: the virtue in calling a spade what it is' in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013).

questionable whether the procedure allows for an effective assessment of the benefits or burdens which ANH brings about for the patient. Literature reviews on ANH were cited in Chapter 1 and 2. These demonstrated that the contribution of ANH is not categorically clear. It may be of benefit for certain patients. Medical futility of ANH is therefore not a certainty in the context of palliative sedation and a case-by-case assessment should be implemented in order to protect the rights of the patient. There would seem to be particular merit in the point advanced by Raus et al. that ‘the decision not to provide ANH seems to imply the moral claim that life is no longer worth prolonging, rather than the medical claim that hydration and nutrition are medically futile’.¹⁵⁴

There should be a distinction between the decisions as they are supported by different legal and ethical principles as was described in Chapter 2. In circumstances where the patient has capacity their informed consent is essential in defining the legality of the practice. This focus on autonomy and patient input is a central tenet of the Claeys-Leonetti law, however it is questionable whether the law delivers on this. Unlike national guidelines in other countries there appears to be little encouragement for healthcare professionals to actively raise end-of-life decisions with patients in a timely manner which allows for their full participation in healthcare decision-making.¹⁵⁵ Furthermore, in circumstances where the patient lacks capacity to express their will it is possible that treatment be stopped and sedation administered in accordance with a collegial procedure. The effect is to end patient autonomy from that point. It should also be noted that the procedure provided for in the law is limited in recognising the significance of religious and personal factors in the context of ANH provision.

6.7.7 The administration of continuous deep sedation

The concept of proportionality is an element which underpins the provision of palliative sedation. Again, this concept was addressed in the KNMG Guideline for Palliative Sedation and it has been recognised as part of good medical practice.¹⁵⁶ Proportionality in sedative use is relevant to justifications such as double effect. The Claeys-Leonetti law as well as the Code of Medical Ethics is silent on this point. Instead, healthcare professionals would need to look beyond the law for guidance. The SFAP have published guidance on sedative medication and the use of midazolam is suggested. However, the lack of reference to proportionality in the Claeys-Leonetti law is notable given its role in defining judicious use of sedation.

154 Raus (note 92) [5].

155 Royal Dutch Medical Association, ‘Guideline for Palliative Sedation’ (Royal Dutch Medical Association 2009); See also A.B. Astrow and B. Popp, ‘The Palliative Care Information Act in real life’ (2011) 364 *New England Journal of Medicine* 1885.

156 Royal Dutch Medical Association (note 155).

6.7.8 Converging practices at the end-of-life?

Does the law undermine the legitimacy of the distinction between specialist palliative care and euthanasia?

The motivation behind the KNMG Guideline for Palliative Sedation in the Netherlands was to underline the legal, ethical, and clinical space between specialist palliative care practices and euthanasia. In contrast to this, it appears as if the Claeys-Leonetti law brought the practices closer together. As such, it is to be questioned whether the law undermines the legitimacy of the distinction between specialist palliative care and euthanasia. The indications for sedation, proportionality, consent, and procedural requirements all have a role in justifying sedation and distinguishing the practice from forms of physician aided dying.

The law can be interpreted in light of the SFAP guidance, however when the law is examined in isolation there are many open-ended elements. The ‘short-term’ timeframe and refractory suffering are not defined by the law. There is no distinction made between somatic and non-somatic suffering. In addition, it appears possible for the patient to bring about continuous deep sedation through the refusal of treatment. However, the lack of certainty is not limited to the indications and preconditions for treatment. There is no reference to proportional use of sedation. The procedural requirements are linked to the collegial procedure. However, the application of Leonetti’s law demonstrated that this process is not consistently adhered to.¹⁵⁷ Furthermore, Horn has previously illustrated the reluctance of healthcare professionals in France to call on specialist palliative care experts.¹⁵⁸ In addition to these elements, the administration of sedation and ANH is presented as a single decision which was shown to be legally and ethically problematic in Chapter 2.

In 2005 Leonetti’s law, through recognition of a possible role for double effect reasoning, provided a legal basis for the practice of sedation in France.¹⁵⁹ Despite this, it was suggested by Leonetti and Claeys that if the practice of sedation already existed in French hospitals ‘it is far from being general and homogeneous’.¹⁶⁰ The Claeys-Leonetti law provides an explicit recognition of the practice but does not bring clarity or consistency to palliative sedation. As is evident from the preceding discussion, a majority of guidance came from the SFAP. Yet, it is questionable how familiar healthcare professionals who are not regularly engaged in the provision of palliative care will be with the SFAP guidance. In sum, the law could facilitate a reduction in the distinction between palliative sedation and euthanasia but this ultimately depends on healthcare professionals in practice. A further point

157 Lesieur (note 100).

158 Horn (note 9).

159 Delbeke (note 93) 136.

160 Béguin (note 125) «Si cette pratique sédative existe déjà dans les hôpitaux français, «elle est loin d’être générale et homogène», avaient constaté les deux auteurs de la proposition de loi.»

to consider is the possible contribution which the law may make in limiting calls for the introduction of euthanasia in France.

Will the law nullify calls for the liberalisation of laws on euthanasia?

The Sicard report concluded that there was no need for the introduction of new legislation to address challenges in end-of-life care. Instead, the issue was to effectively implement existing laws. This did not prevent the introduction of the Claeys-Leonetti law. It is a law which clarified a number of aspects in end-of-life care including advance directives. Nevertheless, legislators used palliative sedation in this law as an attempt to placate both sides of the euthanasia debate. This approach is largely inadequate as it fails to provide clarity for palliative sedation and fails to go far enough for supporters of euthanasia. As stated by Raus et al., 'by missing the opportunity to create clarity on continuous deep sedation, the French legislative initiative has actually resulted in a further polarisation of the debate between proponents and opponents of euthanasia and physician-assisted suicide'.¹⁶¹

It is beyond the scope of this work to engage in detailed discussion about the motivations which underpin requests for euthanasia. Nonetheless, a common refrain behind calls for euthanasia is the fear of pain and a loss of autonomy. The fear of pain as a motivating factor has been underlined by Boulanger et al.¹⁶² and Fohr.¹⁶³ As for autonomy, in Horn's research on euthanasia in France and Germany, she suggested that 'requests for euthanasia are often motivated by the individual's fear of losing autonomy. The requests express the desire of a vulnerable person to reaffirm their liberty – their ultimate liberty in determining their own death'.¹⁶⁴ It has been noted at several points that while the Claeys-Leonetti law seeks to promote patient autonomy this will require patients to be aware of the possibility of requesting palliative sedation. It places patients in a position where they are to be the drivers of their care. In the absence of appropriate information sharing it is unlikely that patients would know of the boundaries of their right to self-determination and how this could influence pain experienced at the end-of-life.

Palliative care will not always address the fear of pain or the concern over the loss of autonomy. For some, the preference would be for a form of physician-aided dying. Ferrand et al. demonstrated the prevalence and persistence of requests for physician aided dying in palliative care units in France and concluded that 'the development of palliative care does not resolve all the situations of request for

161 Raus (note 92) [8].

162 Boulanger (note 150) [4] 'Fear of future pain and minimal quality of life were the main reasons given for the possible wish for euthanasia.'

163 S. Anderson Fohr, 'The double effect of pain medication: separating myth from reality' (1998) 1(4) *Journal of Palliative Medicine* 315.

164 Horn (note 9) 207; C. Scale and J. Addington-Hall, 'Euthanasia: why people want to die earlier' (1994) 39(5) *Social Science and Medicine* 647.

anticipated death'.¹⁶⁵ In short, attempting to nullify calls for the liberalisation of laws on euthanasia through use of palliative sedation represents an ineffective compromise which does not benefit any party involved.

6.7.9 *The impact of the Claeys-Leonetti law*

In considering the impact of the Claeys-Leonetti law to date one of the main questions is whether it has effectively protected and promoted the rights of the patient, and accordingly, has it resulted in better patient care. There are also questions about the clarity it affords for healthcare professionals. In sum, does the law effectively translate the aims of its drafters into practice? Since the introduction of the Claeys-Leonetti law, the SFAP has conducted research on its implementation. An online study was carried out between 3 May and 11 June 2017.¹⁶⁶ There were 1095 respondents including members and non-members of the SFAP. At the time of writing a small amount of the survey data was released on issues such as the categorisation of ANH, ethical difficulties, and the promotion of patient autonomy.

As noted above, there was and is a certain degree of uneasiness in France about the classification of ANH as treatment. This categorisation resulted in difficulty for 24% of survey respondents.¹⁶⁷ This is a large group to be experiencing such difficulty. Yet for a majority (55%) the categorisation as treatment which could be stopped when resulting in unreasonable obstinacy avoided difficulties in certain situations. 11% felt it was of no consequence while for 34% it resulted in difficulties in some situations.¹⁶⁸ In effect, there are a considerable number of cases where the Claeys-Leonetti law has posed additional challenges for the healthcare professional.

Question ten of the survey asked respondents about the right of the patient to seek continuous deep sedation until death. 65% agreed that it results in ethical tensions and difficulties, although 92% of respondents consider it a possible response for the suffering of some patients. Despite this there were fears about the manner in which sedation could be used. Question 11 of the study sought the respondents' views and experience in practice of the possibility of deep sedation until the death of the patient in circumstances where the indications are complied with. Only 6% believed it to be of no consequence. 19% felt it results in difficulties in certain situations and 36% believed it facilitates the management of certain

165 E. Ferrand, and others, 'L'évolution des demandes de mort anticipées exprimées auprès des équipes de soins palliatifs en France' (2012) 11(3) *Médecine Palliative* 121, 130 in Spranzi (note 14) 258.

166 Société Française d'Accompagnement et de Soins Palliatifs, 'Enquête Loi Claeys/Leonetti' <<http://www.sfap.org/actualite/enquete-loi-clayesleonetti>> accessed 4 September 2017.

167 Société Française d'Accompagnement et de Soins Palliatifs, 'Résultats Enquête loi Claeys-Leonetti' <<http://www.sfap.org/system/files/analyse-resultats-enque-loi-clayes-leonetti-vc-graph.pdf>> accessed 4 September 2017.

168 Ibid.

difficulties. Significantly, 38% of respondents were of the opinion that it promotes requests for sedation outside of these indications. This leads to a fear of a slippery slope occurring whereby continuous deep sedation moves closer to the practice of euthanasia without equivalent levels of oversight.¹⁶⁹ In line with this 22% of respondents were of the opinion that the demand for sedation from a patient who decides to stop a treatment promotes requests for sedation outside of these indications; an issue alluded to in the earlier discussion of the Claeys-Leonetti law.

The above discussion suggested that the right to request continuous deep sedation was part of the right of autonomy, albeit subject to the limits of the collegial procedure. Moreover, it was suggested that the law had a considerable drawback as patients needed to be aware of the existence of such a right if it was to be relied on in practice. It is therefore significant that 78% of respondents believed that the new legal framework did not facilitate the patient's self-determination. However, 63% think the law promotes respect for the will of the patient by making him an actor in his care. This is somewhat contradictory but reflects the tension of autonomy and paternalism.

Overall, the experience of the law for SFAP respondents appeared to be positive. 55.2% considered that conditions at the end of life under the new legal framework to be better defined, while 8.6% feel conditions have declined.¹⁷⁰ These figures may reflect broader changes such as the increased clarity which the law brought to advance directives and therefore do not necessarily correspond with changes in sedative practice. In any case, it will be important to monitor the use of continuous deep sedation in France over the coming years in order to identify any nascent trends in practice.

6.8 Conclusion

This chapter sought to examine the use of legislation in France as a way of bringing about change in practice. Throughout the chapter it was important to be cognisant of the broader legal and social context which influenced and motivated the introduction of legislation. France is notable for the multiple pieces of legislation which address the provision of palliative care but also has a culture of medical care deeply rooted in a paternalistic tradition. In many respects, the legislation is representative of a tension which exists between those demanding greater patient self-determination and those who are more closely attached to medical paternalism.

Early legislation on this topic recognised a right to access palliative care. Law n° 2005-370 acknowledged double effect, while the more recent Claeys-Leonetti law

169 M. Battin, 'Terminal sedation: recasting a metaphor as the *ars moriendi* changes' in S. Sterckx and others, *Continuous Sedation at the End of Life* (Cambridge University Press 2013) 243 'Indeed, direct aid-in-dying, at least as it is legally practiced in, for example, Oregon, requires a series of safeguards – confirmation of a terminal diagnosis, oral and written requests, a waiting period and other criteria. The practice of terminal sedation, on the other hand, is not subject to legally binding safeguards.'

170 SFAP (note 167) 21.6% unchanged, 14.6% other.

provided for a right to request continuous deep sedation. The Claeys-Leonetti law was the focal point for much of the discussion in this chapter. There were clear points of criticism on the indications for sedation, proportionality, consent, and procedural requirements. However, this is not to suggest that the use of legislation in this context is always inappropriate. Legislation can underline points of ethical contention and address these issues in a transparent manner. In doing so, legislation can establish the legitimacy of the distinction between specialist palliative care practices and euthanasia. Moreover, guidance such as that issued by SFAP can ensure the law remains relevant and reflects developments in medical practice. This is a difficult balance to achieve.

At the outset, it was stated that it would be argued that legislation can have a significant role but that the use of palliative care legislation to evade political debate on euthanasia is inappropriate regardless of jurisdiction. Key aspects of the Sicard report were dispensed with in pursuing further legislation on end-of-life practices. The basis for this can be traced back to campaign pledge 21 of the 2012 French presidential election. The law represents an unfortunate compromise which further obscures the limits of care at the end-of-life. As euthanasia is not a substitute for palliative care, neither is palliative care a substitute for euthanasia.

Conclusion

Law, palliative care and dying

Francis Bacon set out that '[m]en fear death as children fear to go in the dark.'¹ This fear is exacerbated by concerns over pain and symptom management which, in turn, leads to calls for the liberalisation of the law on euthanasia.² This work set out to address areas of darkness, areas of ambiguity, which persist in palliative and specialist palliative care. The Introduction opened with a quote from Philip Larkin which underlined the nature and reality of death. All of which frames the importance of this topic.

The central theme of this work is the importance and role of an appropriate legal framework to guide specialist palliative care practices. It has been argued that it is an essential but often overlooked component in good care. As noted in the Introduction, the legal framework has a vital role in demarcating the bounds of palliative care provision through reference to human rights, normative concepts, and ethical justifications which frame the legitimacy of clinical practice. This conclusion will draw together the overarching themes which have been developed in this work. These include discussion of the legitimacy of the distinction between specialist palliative care practices and euthanasia, as well as reflecting on the influence of human rights in palliative care. The third section will broadly address the role of the law. In particular, it is suggested that law may act as a tool through which we attempt to shape and, in some respects, secure the concept of a good death. This may not always be possible to achieve but, at a minimum, the legal framework should not act as an impediment to the delivery of appropriate care.

The legitimacy of the distinction between specialist palliative care practices and euthanasia

In Chapter 2 the points of similarity between specialist palliative care practices and euthanasia were outlined. The Netherlands was drawn on to illustrate these points of convergence. It was recognised that this provided a snapshot of the law on euthanasia and is not necessarily reflective of all other jurisdictions. Nonetheless,

1 F. Bacon, *The Major Works* (Oxford University Press 2008) 343.

2 S.A. Fohr, 'The double effect of pain medication: separating myth from reality' (1998) 4(1) *Journal of Palliative Medicine* 315, 326.

this chapter demonstrated an overlap in the indications for voluntary active euthanasia and palliative sedation. In both, the patient must be suffering unbearably and this suffering should be untreatable. The broad shapes of these practices appear to overlap but there are differences in the decision-making framework, the type of drugs selected, the administration of drugs, and the intention of the healthcare professional. This does not diminish the seriousness of applying labels such as ‘slow euthanasia’,³ ‘backdoor euthanasia’,⁴ or false equivalencies which are made in media reporting of palliative sedation. In the absence of a clearly defined legal basis, the doctrine of double effect assumes an important role in providing a justification for the administration of palliative sedation.

Over the course of Chapter 2 it was argued that the doctrine of double effect is inadequate and is now more of a hindrance in many respects. This emerged through discussion of the criteria for double effect, its place in law, and the realities of medical practice. The criteria for double effect are subject to multiple interpretations which hampers a consistent application of the doctrine. It was argued that the four criteria for double effect could be satisfied but this proved more challenging when it was the reduction in consciousness which was the perceived harm. The basis for a distinction grounded in the doctrine of double effect is often precarious and influenced by subjective interpretation. Cases linked to double effect reasoning were set out but the doctrine has not been clearly enunciated in law. As stated by Lord Mustill in *Bland*, the doctrine of double effect has not ‘been the subject of a specific decision but seems to have been generally assumed to be the law by criminal practitioners’.⁵ Furthermore, changes in sedative drugs and other developments in palliative medicine mean that reference to double effect raises connotations which do not necessarily reflect medical practice. The administration of sedation is not a once-off decision but is a process thereby allowing multiple intentions to exist and develop over time. The decision often involves the input of a multidisciplinary team rather than being made by a single isolated medical practitioner. The doctrine of double effect provides little assistance in navigating such legal and ethical complexities.

The issue is further exacerbated by the decision to withdraw or withhold artificial nutrition and hydration. These are separate decisions and are distinct from the administration of sedation. However, the proximity between these practices can lead to suggestions that a single decision is taken and the distinction between the practices is ignored. This would have a negative effect on the distinction between euthanasia and specialist palliative care practices. The decision to withdraw or withhold ANH can be made in several ways. It may be based on the patient’s refusal of treatment or, an assessment of a patient’s best interests in circumstances where they lack capacity. Such decisions are to be made on a case-by-case

3 J.A. Billings and S.D. Block, ‘Slow euthanasia’ (1996) 12 *Journal of Palliative Care* 21.

4 S. Gevers, ‘Terminal sedation: a new legal approach’ (2003) 10 *European Journal of Health Law* 359, 360; Select Committee on Dying with Dignity (Québec, March 2012) 38.

5 *Airedale N.H.S. v Bland* [1993] AC 789, 892.

basis and a policy of always or never providing ANH is not appropriate. In effect, this chapter began to draw out the challenges in decision-making and the role of the law in providing a level of oversight as well as support.

In sum, in Chapter 2 it was argued that the reliance on double effect as a justification for palliative sedation reinforces the suggestion that there is a link between euthanasia and specialist palliative care. It suggests there is a practice which needs to be justified or excused and it does not represent a good compromise position for those on either side of the debate. Regardless of the broader issues and criticisms surrounding the doctrine, it is wholly inappropriate for palliative sedation to be guided by an ethical justification. The doctrine of double effect provides no real guidance on appropriate medical treatment and care. A failure to address these issues in a transparent manner may ultimately do more harm to both the patient and the medical specialty. As Quill et al. stated, 'hidden, ambiguous practices, inconsistent justifications, and failure to acknowledge the risks of accepted practices may also undermine the quality of terminal care and put patients at unwarranted risk.'⁶ Consequently, this chapter raised the question of how the legal framework can inhabit the space of double effect and bring clarity and consistency to decision-making for specialist palliative care.

The human rights framework for palliative care

The human rights framework for palliative care was addressed in Chapter 3. It would easily be possible to devote a full work to exploring the influence of human rights in palliative care. This work concentrated on the right of autonomy, physical integrity, protection from inhuman or degrading treatment, the concept of dignity, and the right to palliative care. Human rights have a valuable role in defining a minimum standard of care and are a tool for advocacy. Yet, it can be challenging to effectively distil the meaning and duties of human rights so as to embed them in practice.

The importance of autonomy was set out early in Chapter 3. The exercise of the right of autonomy informs concepts such as the 'quality of life' and the nature of suffering. The protection and promotion of autonomy is therefore an important facet of palliative care provision. This is underlined by the European Association of Palliative Care, '[r]espect for autonomy is an important goal of palliative care which seeks to strengthen and restore autonomy and not to destroy it.'⁷ The empirical research that was cited served to underline the challenge of achieving this. Patients at the end of life are often in a vulnerable position. Consequently, healthcare professionals and family members may wish to shield the patient from potentially distressing conversations and decisions. This exclusion can lead to

6 T.E. Quill and others, 'Palliative Options of Last Resort: A Comparison of Voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia' in T. Tännsjö, *Terminal Sedation: Euthanasia in Disguise?* (Kluwer Academic Publishers 2004) 11.

7 L.J. Materstvedt, and others, 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force' (2003) 17 *Palliative Medicine* 97, 98.

greater uncertainty for the patient. A significant point which emerged from the discussion of autonomy was the need to be proactive in engaging with the patient. The benefits of a proactive approach were highlighted in the Dwyer and McCarthy study where it was suggested that ‘palliative sedation could be discussed much earlier in the patient’s disease trajectory and they saw this as a means of promoting the patient’s autonomy.’⁸ A proactive approach is also evident in the Dutch guidelines for palliative sedation and is a key feature of the New York State Palliative Care Information Act.⁹ There will of course be cases where the patient lacks sufficient capacity to contribute to the decision-making process and autonomy may not always be a useful guide. In this respect, the discussion of human rights turned to consider the influence of dignity and closely related rights.

Dignity is a concept which defies simple definition and it has been described as ‘an individual concept’.¹⁰ Chapter 3 examined several rights which have a prominent role in upholding human dignity. The right to be protected from inhuman or degrading treatment was among these rights. There is a high threshold for successfully relying on Article 3 and this has had the effect of limiting its use. This high threshold was evidenced in *D v United Kingdom* as it appears that a complete lack of medical care or inadequate medical care would be required to give rise to a breach of Article 3.¹¹ Linked to palliative care, it can be suggested that laws on opioid availability, access to medical care at the end-of-life, and inadequate prescribing guidelines can result in the engagement of this right. These points are echoed in comments by the SR on Torture in setting out that the denial of pain treatment could result in cruel, inhuman, or degrading treatment. Although it is unlikely that this right would be breached in Ireland or the UK, there are many jurisdictions where much greater steps are required to ensure adequate pain and symptom management is available and accessible. In the context of the ECHR it establishes a minimum standard of care while also placing an obligation on the State to investigate potential breaches of the right, as well as establishing an obligation to ensure the availability and accessibility of medicines for pain relief. Tied to this is the structure of the decision-making framework which also has a substantial role as illustrated by *Tysiqc v Poland*.¹²

Calls for a right to palliative care have been made in numerous declarations yet there is little basis for an explicit right to palliative care in the domestic legal systems of Ireland and England and Wales, thereby undermining its practical relevance. Moreover, it was suggested that this right can often be reduced to a right to pain management and can rarely be relied on by the patient in their

8 I. Dwyer and J. McCarthy, ‘Experiences of palliative care nurses in the utilisation of palliative sedation in a hospice setting’ (2016) 6 *End of Life Journal* 5.

9 A.B. Astrow and B. Popp, ‘The Palliative Care Information Act in Real Life’ (2011) 364 *New England Journal of Medicine* 1885.

10 L. Radbruch and others, ‘White Paper on standards and norms for hospice and palliative care in Europe: part 1’ (2009) 16(6) *European Journal of Palliative Care* 278, 283.

11 *D v United Kingdom* (1997) 24 EHRR 423.

12 *Tysiqc v Poland* (2007) 45 EHRR 42.

individual circumstances. Chapter 3 suggested that rights with a clear basis in the ECHR and in the domestic system may prove a more effective tool in improving the provision of palliative care. This is not to suggest that the right to health and its role in advancing a right to palliative care cannot be beneficial at the international level.

There are limits to the contribution a human rights framework can make. For instance, the assertion of these rights may require a court challenge. This may not be possible given the condition of the patient and, in such cases, retrospective failures are not easily resolved. The financial cost of litigation may also prove prohibitive in fully realising these rights in palliative and specialist palliative care. Despite this, it can be recognised that individual actions could be taken based on a breach of contract, elder abuse, negligence, or a failure to adhere to professional standards and guidelines. A considerable range of litigation options is therefore available which reflects how many of these rights are encapsulated in elements of the wider legal framework.

A contemporary *ars moriendi* in law

Chapters 4, 5, and 6 examined the legal framework in Ireland, England and Wales, the Netherlands, and France. Each jurisdiction sought to define the role of palliative care in a slightly different manner. This was linked to the development of palliative care and the cultural background in the jurisdiction which established certain priorities. The legal framework in Ireland, and England and Wales was shown to be fragmented and provided little specific detail on specialist palliative care practices. In contrast, the legal framework in the Netherlands and France was shown to be more detailed but also demonstrated an uneasy relationship between euthanasia and palliative sedation. This tension in the legal framework was reflective of a broader concern about the oversight and limits of care. The distinction cannot be fully explained on the basis of the common and civil law traditions. The Netherlands opted for a framework based on enforceable professional guidance whereas France consistently pursued a legislative solution. Nonetheless, each approach addressed common components of palliative and specialist palliative care. In broad terms these included: access to palliative care; quality of care; preferred place of death; professional competencies; advance care planning; and pain and symptom control. The concept of a ‘good death’ is pursued through these factors and is given a legal grounding in these systems. The difference between jurisdictions arose in the level of clarity and consistency which the framework promoted.

The strategy and planning documents in England rarely engaged with the legal framework. It has been an overlooked element in the provision of palliative care. This is reflected in the poor awareness of the Mental Capacity Act 2005. Chapter 4 examined the General Medical Council, the National Institute for Health and Care Excellence, failings of the Liverpool Care Pathway, and attempts to legislate for palliative care. The General Medical Council’s guideline titled ‘Treatment and care towards the end of life’ was shown to provide substantial guidance but there are shortcomings around sedation and treatment withdrawal. A persistent

challenge in England is inconsistent provision of palliative care across the country. The emerging legislative approach is notable as it demonstrates an attempt to influence palliative care resource provision.¹³ Although the Access to Palliative Care Bill 2015 failed, it drew attention to two points. First, it underlined the challenge of securing minimum standards in circumstances where local policy is preferred to national initiatives. Second, the 2015 Bill highlighted how the legal framework can support and promote palliative care in ways other than addressing specialist palliative care practices. The French legal framework also drew attention to this point in the context of caregiver's leave for family members or persons living in the home. It would appear that England is slowly moving towards a legislative response but this tension between local autonomy and national standards will need to be carefully navigated.

Ireland has no legislation directly addressing the provision of palliative and specialist palliative care. The Assisted Decision-Making (Capacity) Act 2015 will be of relevance once commenced but, at present, the legal framework is largely based on professional standards and guidelines issued by the Irish Medical Council and the Nursing and Midwifery Board of Ireland. In addition, requirements for local policies lead to different decision-making frameworks between palliative care providers. In a study by O'Leary and Tiernan, a nurse manager proposed that '[c]lear national guidelines need to be put in place to ensure uniformity when dealing with nonmalignant patients requiring palliative care.'¹⁴

The law on euthanasia was shown to be a significant motivating factor behind the legal framework for palliative care in the Netherlands and France. This results in competing interests which are not easily satisfied. Over the course of Chapters 5 and 6 it was suggested that professional guidelines in the Netherlands emphasised the distinction while the recent law in France has in some ways narrowed the perceived distance between euthanasia and palliative sedation.

The Netherlands eschewed legislation in favour of professional guidelines on palliative sedation issued by the Koninklijke Nederlandsche Maatschappij tot bevordering der Geneeskunst (Royal Dutch Medical Association) (KNMG). The reliance placed on professional standards in the Netherlands demonstrated a move away from a justification led approach to specialist palliative care and instead signalled a more active approach in defining this area of care and ensuring that it was provided in a manner which was legally and ethically sound for both the healthcare professional and the patient. Although the guideline was largely effective in defining palliative sedation as normal medical practice there are elements where it does not fully engage with contentious aspects of the practice. In this respect, there is a need to acknowledge aspects of specialist palliative care which may be contentious and in need of greater oversight in the decision-making framework. A failure to address such points could hamper the legitimacy of the practice in the long-term.

13 Access to Palliative Care Bill 2017.

14 N. O'Leary and E. Tiernan, 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers' (2008) *Palliative Medicine* 77, 79.

In contrast, France does not provide for physician assisted suicide or euthanasia within its legal framework. However, it was shown that calls for a change in the legal status of euthanasia have often been met with a response based on palliative care. Law n° 91-748 of 31 July 1991 set palliative care as part of the duty of all hospitals, and Kouchner's law set out that every person has the right to receive care so as to relieve pain. In addition, Leonetti's law of 2005 sought to bring legislative clarity to healthcare decision-making at the end-of-life. Along with the Code of Medical Ethics there was a clear basis in law for the provision of palliative sedation. Law n° 2016-87 went further than previous legislation and went beyond the approach taken in any other jurisdiction. Article 3 of this law provides that a patient can request deep and prolonged sedation so as to avoid all pain. This is not as broad as it may first appear as certain indications and preconditions must exist and the decision largely rests with the medical practitioner. Nonetheless, the use of palliative sedation in this law underlines the importance of guarding against injudicious use of sedation. In particular, it was set out in Chapter 6 that as euthanasia is not a substitute for palliative care, neither is palliative care a substitute for euthanasia. In any case, it raises the question of what role should the law have in shaping palliative care.

This work argued for a clear legal framework to guide palliative and specialist palliative care. It is not appropriate for healthcare professionals to practise in a legal vacuum but instead should be 'governed by rules which are fixed, knowable, and certain'.¹⁵ There is an opportunity in Ireland, and England and Wales to provide more detailed guidance absent the influence or demands for euthanasia which exist elsewhere. As latter chapters demonstrated, legislation and professional guidelines each have strengths and weaknesses. Legislation provides a strong statement of the law and can underline the legitimacy of specialist palliative care practices. Guidelines, such as those issued by the KNMG or the SFAP, ensure the law remains relevant and reflects developments in medical practice.

Effective use of the legal framework can provide an avenue for the continued promotion and advancement of palliative care. Furthermore, closer legal engagement in palliative and specialist palliative care can promote transparency in decision-making and can prove valuable for both the healthcare professional and the patient. As Donnelly stated, '[i]f the law is not concerned about maintaining legal standards, it is difficult to see why healthcare professionals should be expected to be.'¹⁶

In sum, the legal framework can shape and influence the provision of palliative care in a multitude of ways and should not be overlooked. Yet, palliative care solely based on law would be poorer. Palliative care also requires appropriate training, resources, and broader supports if care which improves the quality of life and relieves suffering through treatment of pain and other problems, physical, psychosocial, and spiritual is to be provided. In effect, developments in this area

15 J. Raz, *The Authority of Law* (Oxford University Press 1979) 214–15.

16 M. Donnelly, *Healthcare Decision-Making and the Law* (Cambridge University Press 2014) 276.

require the input and knowledge of healthcare professionals if they are to prove beneficial and effective. A framework which provokes a legalistic or box-ticking approach is to be avoided. Instead, the patient should be central to the legal framework and an individualised assessment made by the healthcare professional.

Conclusion: the way forward

The early pages of this work set out the importance of palliative care both now and in the future. It is essential that any ambiguity attaching to palliative or specialist palliative care practices is addressed in a manner which clarifies the limits of care and facilitates consistency in decision-making. This work has argued that greater attention must be given to the legal framework as a factor which informs and shapes the practice of palliative and specialist palliative care. This comprises legal and ethical justifications, human rights, and the decision-making framework for various practices. Yet, there are many more areas beyond this which need to be explored in more detail. These include areas such as paediatric palliative care, equality of palliative care provision for the LGBTQ community, and a greater focus on the role of nurses and other professions which contribute to the multi-disciplinary care of the patient. Furthermore, opioid accessibility continues to be a challenge in many jurisdictions where legal barriers curtail the provision of care. This work has addressed a small portion of the legal challenges which exist in this area. Overall, developments in the legal framework need not stymie the progress of palliative care but should complement and provide a way of contributing to the continued development of the practice.

Bibliography

- 'A plea for beneficent euthanasia' (1974) 34(4) *Humanist* 4.
- Abarshi, E., and Payne, S., 'Awareness of the EAPC recommendations on palliative sedation: a web-based survey' (2014) 21(2) *European Journal of Palliative Care* 81.
- Addington-Hall, J., and Hunt, K., 'Non-cancer Patients as an Under-served Group' in Cohen, J., and Deliens, L., (eds) *A Public Health Perspective on End of Life Care* (Oxford University Press 2012).
- Aitken-Swan, J., and Paterson, R., 'The cancer patient: delay in seeking advice' (1955) 1 *British Medical Journal* 623.
- Ahmedzai, S.H., Costa, A., Blengini, C., Bosch, A., Sanz-Ortiz, J., Ventafridda, V., and Verhagen S.C., 'A new international framework for palliative care' (2004) 40(15) *Eur J Cancer* 2192.
- Alpers, A., 'Criminal act or palliative care? Prosecutions involving the care of the dying' (1998) 26 *Journal of Law, Medicine and Ethics* 308.
- American Medical Association, 'The AMA Code of Medical Ethics' opinion on sedation at the end of life' (2013) 15(5) *American Medical Association Journal of Ethics* 428.
- An Bord Altranais, 'Practice Standards for Nurses and Midwives with Prescriptive Authority' (September 2010).
- Aquinas, T., *Summa Theologica* (Fathers of the English Dominican Province tr, Benziger Brothers 1947).
- Arevalo, J.J., Brinkkemper, T., van der Heide, A., Rietjens, J.A., Ribbe, M., Deliens, L., Loe, S.A., Zuurmond, W.W., and Perez, R.S., 'Palliative sedation: reliability and validity of sedation scales' (2012) 44(5) *Journal of Pain and Symptom Management* 704.
- Arevalo, J.J., Rietjens, J.A., Swart, S.J., Perez, R.S., and van der Heide, A., 'Day-to-day care in palliative sedation: Survey of nurses' experiences with decision-making and performance' (2013) 50 *International Journal of Nursing Studies* 613.
- Ariès, P., *The Hour of Our Death* (Random House 1991).
- Ariès, P., *Western Attitudes toward Death: From the Middle Ages to the Present* (P. Ranum tr, John Hopkins University Press 1975).
- Arnold, E., Finucane, A.M., and Oxenham, D., 'Preferred place of death for patients referred to a specialist palliative care service' (2015) 5(3) *BMJ Supportive & Palliative Care* 294.
- Ashby, M., 'Death Causation in Palliative Medicine' in Freckelton, I. and Mendelson, D., (eds), *Causation in Law and Medicine* (Ashgate/Dartmouth 2002).
- Ashby, M.A., and Mendelson, D., 'Gardner; re BWV: Victorian Supreme Court makes landmark Australian ruling on tube feeding' (2004) 181(8) *Med J Aust* 442.

- Ashby, M., and Stoffell, B., 'Artificial hydration and alimentation at the end of life: a reply to Craig' (1995) 21(3) *Journal of Medical Ethics* 135.
- Ashworth, A., *Principles of Criminal Law* (3rd edn, Oxford University Press 1999).
- Astrow, A.B., and Popp, B., 'The Palliative Care Information Act in real life' (2011) 364 *N Engl J Med* 1885.
- Baas, A.A., Zyllicz, Z., and Hesselmann, G.M., 'Dyspnoea' (Integraal Kankercentrum Nederland 2014).
- Bacon, F., *The Major Works* (Oxford University Press 2008).
- Bailey, M., 'A survey of the social needs of patients with incurable lung cancer' (1959) 11 *The Almoner* 379.
- Baines, M., 'From pioneer days to implementation: lessons to be learnt' (2011) 18(5) *European Journal of Palliative Care* 223.
- Baines, M., 'Pioneering days of palliative care' (2011) 18(5) *European Journal of Palliative Care* 223.
- Baines, M., 'The origins and development of palliative care at home' (2010) 18(1) *Progress in Palliative Care* 4.
- Bannink, M., de Graeff, A., and Monster, H., 'Delirium' (Integraal Kankercentrum Nederland 2010).
- Barathi, B., and Chandra, P.S., 'Palliative sedation in advanced cancer patients: does it shorten survival time? – A systematic review' (2013) 19(1) *Indian Journal of Palliative Care* 40.
- Barcelona Declaration on Palliative Care* (1995) 3(1) *European Journal of Palliative Care* 15.
- Battin, M., 'Terminal sedation: pulling the sheet over our eyes' (2008) 38(5) *Hastings Center Report* 27.
- Battin, M., 'Terminal Sedation: Recasting a Metaphor as the *Ars Moriendi* Changes' in Sterckx, S., Raus, K., and Mortier, F., (eds) *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Baumann, A., Audibert, G., Claudot, F., and Puybasset, L., 'Ethics review: end of life legislation – the French model' (2009) 13(1) *Critical Care* 204.
- Beauchamp, T.L., and Childress, J.F., *Principles of Biomedical Ethics* (7th edn, Oxford University Press 2013).
- Beel, A., McClement, S.E., and Harlos, M., 'Palliative sedation therapy: a review of definitions and usage' (2002) 8(4) *International Journal of Palliative Nursing* 190.
- Begley, A.M., 'Acts, omissions, intentions and motives: a philosophical examination of the moral distinction between killing and letting die' (1998) 28(4) *Journal of Advanced Nursing* 865.
- Béguin, F., «La loi Claeys-Leonetti sur la fin de vie définitivement adoptée» *Le Monde* (Paris, 27 January 2016) <http://www.lemonde.fr/societe/article/2016/01/27/fin-de-vie-cc-que-va-changer-la-nouvelle-loi-claey-leonetti_4854266_3224.html> (accessed 4 September 2017).
- Bell, D., 'GMC guidance on end of life care' (2010) 340 *The BMJ* 3231.
- Belverud, S., Mogilner, A., and Schulder, M., 'Intrathecal pumps' (2008) 5(1) *Neurotherapeutics* 114.
- Bernheim, J.L., and Raus, K., 'Euthanasia embedded in palliative care. Responses to essentialistic criticisms of the Belgian model of integral end-of-life care' (2017) 43 *Journal of Medical Ethics* 487.
- Biggs, H., 'Euthanasia and death with dignity: still poised on the fulcrum of homicide' (1996) *Criminal Law Review* 878.

- Billings, J.A., and Block, S.D., 'Slow euthanasia' (1996) 12 *Journal of Palliative Care* 21.
- Bilsen, J., Cohen, J., Chambaere, K., and Posset, G., 'Medical end-of-life practices under the euthanasia law in Belgium' (2009) 361 *N Engl J Med* 1119.
- Binchy, W., 'Dignity as a Constitutional Concept' in Carolan, E., and Doyle, O., (eds), *The Irish Constitution: Governance and Values* (Round Hall 2008).
- Blank, R.H., 'End-of-life decision making across cultures' (2011) 39 *Journal of Law, Medicine and Ethics* 201.
- Bolognesi, D., Centeno, C., and Biasco, G., '*Specialisation in Palliative Medicine for Physicians in Europe: A Supplement of the EAPC Atlas of Palliative Care in Europe*' (EAPC Press 2014).
- Boseley, S., 'Four in 10 hospitals told to improve care for the dying' *The Guardian* (London 3 February 2016).
- Boulanger, A., Chabal, T., Fichaux, M., Destandau, M., La Piana, J.M., Auquier, P., Baumstarck, K., and Salas, S., 'Opinions about the new law on end-of-life issues in a sample of French patients receiving palliative care' (2017) 16 *BMC Palliative Care* 7.
- Boyle, J., 'Medical ethics and double effect: the case of terminal sedation' (2004) 25 *Theoretical Medicine* 51.
- Brandt, H.E., Deliens, L., Ooms, M.E., van der Steen, J.T., van der Wal, G., and Ribbe, M.W., 'Symptoms, signs, problems, and diseases of terminally ill patients: a nationwide observational study in the Netherlands' (2005) 165(3) *Arch Intern Med* 314.
- Breitbart, W., Marotta, R., Platt, M.M., Weisman, H., Derevenco, M., Grau, C., Corbera, K., Raymond, S., Lund, S., and Jacobson, P., 'A double-blind trial of haloperidol, chlorpromazine, and lorazepam in the treatment of delirium in hospitalized AIDS patients' (1996) 153(2) *Am J Psychiatry* 231.
- Brennan, F., 'Dignity: a unifying concept for palliative care and human rights' (2014) 22(2) *Progress in Palliative Care* 88.
- Brennan, F., 'Paediatric Palliative Care as a Basic Human Right' in Pfund, R. and Fowler-Kerry, S. (eds) *Perspectives on Palliative Care for Children and Young People: A Global Discourse* (CRC Press 2010)
- Brennan, F., 'Palliative care as an international human right' (2007) 33(5) *Journal of Pain and Symptom Management* 494.
- Brinkkemper, T., Klinkenberg, M., Deliens, L., Eliel, M., Rietjens, J.A., Zuurmond, W.W., and Perez, R.S., 'Palliative sedation at home in the Netherlands: a nationwide survey among nurses' (2011) 67(8) *Journal of Advanced Nursing* 1719.
- Brinkman, A., and Gootjes, J., 'NPTN: palliative care comes under the spotlight in the Netherlands' (2009) 16(3) *European Journal of Palliative Care* 151.
- Brody, H., 'Commentary on Billings and Block's "Slow Euthanasia"' (1996) 12 *Journal of Palliative Care* 38.
- Broeckaert, B., and Olarte, J.M.N., 'Sedation in Palliative Care: Facts and Concepts' in ten Have, H., and Clark, D., *The Ethics of Palliative Care – European Perspectives* (Open University Press 2002).
- Brown, M.A., Sampson, E.L., Jones, L., and Barron, A.M., 'Prognostic indicators of 6-month mortality in elderly people with advanced dementia: a systematic review' (2013) 27(5) *Palliative Medicine* 389.
- Bruce, A., and Boston, P., 'Relieving existential suffering through palliative sedation: discussion of an uneasy practice' (2011) 67(12) *Journal of Advanced Nursing* 2732.
- Bruinsma, S.M., Rietjens, J.A.C., and van der Heide, A., 'Continuous Sedation until Death: State of the Art' in Sterckx, S., Raus, K., and Mortier, F., (eds) *Continuous*

- Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Buchanan, A.E., and Brock, D.W., *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press 1989).
- Bulli, F., Miccinesi, G., Biancalani, E., Fallai, M., Mannocci, M., Paci, E., Piazza, M., Tempestini, C., and Morino, P., 'Continuous deep sedation in home palliative care units: case studies in the Florence area in 2000 and in 2003–2004' (2007) 73(5) *Minerva Anestesiol* 291.
- Bush, S.H., Grassau, P.A., Yarmo, M.N., Zhang, T., Zinkie, S.J., and Pereira, J.L., 'The Richmond Agitation-Sedation Scale modified for palliative care inpatients (RASS-PAL): a pilot study exploring validity and feasibility in clinical practice' (2014) 13 *BMC Palliative Care* 17.
- Cairns, W., 'The problem of Definitions' (2001) 9(5) *Progress in Palliative Care* 187.
- Callahan, D., 'Autonomy: a moral good, not a moral obsession' (1984) 14(5) *Hastings Center Report* 40.
- Campbell, L., Kilcommins, S., and O'Sullivan, C., *Criminal Law in Ireland: Cases and Commentary* (Clarus Press 2010).
- Caraceni, A., Cherny, N., Fainsinger, R., Kaasa, S., Poulain, P., Radbruch, L., and De Conno, F., 'Pain measurement tools and methods in clinical research in palliative care: recommendations of an Expert Working Group of the European Association of Palliative Care' (2002) 23(3) *Journal of Pain and Symptom Management* 239.
- Care Quality Commission, *The State of Care in NHS Acute Hospitals: 2014 to 2016* (Care Quality Commission 2017).
- Castra, M., *Bien mourir: Sociologie des soins palliatifs* (Presses Universitaires de France 2003).
- Cellarius, V., '“Early terminal sedation” is a distinct entity' (2011) 25(1) *Bioethics* 46.
- Centeno, C., Clark, D., Lynch, T., Rocafort, J., Flores, L.A., Greenwood, A., Brasch, S., Prail, D., Giordano, A., and de Lima, L., *EAPC Atlas of Palliative Care in Europe* (IAHPC Press 2007).
- Centeno, C., Lynch, T., Donea, O., and Clark, D., *EAPC Atlas of Palliative Care 2013* (EAPC Press 2013).
- ChambaereK., Bilsen, J., Cohen, J., Rietjens, J.A., Onwuteaka-Philipsen, B.D., Mortier, F., and Deliens, L., 'Continuous deep sedation until death in Belgium: a nationwide survey' (2010) 170(5) *Arch Intern Med* 490.
- Chan, S.W., 'Montgomery and informed consent: where are we now?' (2017) *British Medical Journal* 357.
- Chater, S., Viola, R., Paterson, J., and Jarvis, V., 'Sedation for intractable distress in the dying – a survey of experts' (1998) 12 *Palliat Med* 255.
- Cherny, N., Fallon, M., Kaasa, S., Portenoy, R.K., and Currow, D.C., (eds) *Oxford Textbook of Palliative Medicine* (5th edn, Oxford University Press 2015).
- Cherny, N.I., 'Sedation in response to refractory existential distress: walking the fine line' (1998) 16 *Journal of Pain Symptom Management* 404.
- Cherny, N.I., and Portenoy, R.K., 'Sedation in the management of refractory symptoms: guidelines for evaluation and treatment' (1994) 10 *Journal of Palliative Care* 31.
- Cherny, N.I., Radbruch, L., and The Board of the European Association for Palliative Care, 'European Association for Palliative Care (EAPC) recommended framework for the use of sedation in palliative care' (2009) 23(7) *Palliat Med* 581.
- Cherny, N., Ripamonti, C., Pereira, J., Davis, C., Fallon, M., McQuay, H., Mercadante, S., Pasternak, G., and Ventafridda, V., 'Strategies to manage the adverse effects of oral morphine: an evidence-based report' (2001) 19(9) *Journal of Clinical Oncology* 25.

- Chochinov, H., 'Address to Standing Committee on Social Affairs, Science and Technology. *Quality End-of-Life Care: The Rights of Every Canadian*' (Senate of Canada 2000).
- Chochinov, H.M., 'Dying, dignity, and new horizons in palliative end-of-life care' (2006) 56(2) *A Cancer Journal for Clinicians* 84.
- Chochinov, H.M., McClement, S.E. and Krendtser, M.S. 'Dignity and Palliative End-of-Life Care' in Cherny, N., Fallon, M., Kaasa, S., Portenoy, R.K., and Currow, D.C., (eds) *Oxford Textbook of Palliative Medicine* (5th edn, Oxford University Press 2015).
- Chrétien S., Moncel, D., Louvel, J.P., Jousselein, C., and Laouenan S., 'End of life, promoting the collegial procedure' (2015) 800 *Soins: la Revue de Référence Infirmière* 25.
- Circulaire relative à l'organisation des soins et à l'accompagnement des maladies en phase terminale, Paris, le 26 août 1986.
- Claessens, P., Menten, J., Schotsmans, P., and Broeckaert, B., 'Palliative sedation: a review of the research literature' (2008) 36(3) *Journal of Pain and Symptom Management* 310.
- Claessens, P., Menten, J., Schotsmans, P., and Broeckaert, B., 'Palliative sedation, not slow euthanasia: a prospective, longitudinal study of sedation in Flemish palliative care units' (2011) 41(1) *Journal of Pain and Symptom Management* 14.
- Clark, D., 'From margins to centre: a review of the history of palliative care in cancer' (2007) 8 *Lancet Oncology* 430.
- Clark, D., 'Hospice and Palliative Care: Developments, Differences, and Challenges' in Youngner, S.J., and Arnold, R.M., (eds) *The Oxford Handbook of Ethics at the End of Life* (Oxford University Press 2016).
- Clark, D., 'Palliative care history: a ritual process?' (2000) 7(2) *European Journal of Palliative Care* 50.
- Clark, D., 'The Rise and Demise of the "Brompton Cocktail"' in Meldrum, M.L., (ed.), *Opioids and Pain Relief: A Historical Perspective* (IASP Press 2003).
- Clark, D., *To Comfort Always: A History of Palliative Medicine since the Nineteenth Century* (Oxford University Press 2016).
- Clark, D., ten Have, H., and Janssens, R., 'Conceptual Tensions in European Palliative Care' in ten Have, D., and Clark, D., (eds) *The Ethics of Palliative Care: European Perspectives* (Oxford University Press 2002).
- Clavreul, L., «Le Comité d'éthique divisé sur l'aide à mourir» *Le Monde* (1 July 2013).
- Clavreul, L., «Fin de vie : la volonté et les droits des patients doivent être mieux pris en compte» *Le Monde* (23 October 2014).
- Cohen, J., and Deliens, L., 'Applying a Public Health Perspective to End-of-Life Care' in Cohen, J., and Deliens, L., (eds) *A Public Health Perspective on End of Life Care* (Oxford University Press 2012).
- Comité Consultatif National d'Éthique, «Rapport du CCNE sur le débat public concernant la fin de vie» (21 octobre 2014).
- Conseil national de l'Ordre des médecins, 'Code de Déontologie Médicale' (avril 2017).
- Council of Europe, 'Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care' (CM (2003) 130).
- Cowan, J.D., and Walsh, D., 'Terminal sedation in palliative medicine – definition and review of the literature' (2001) 9 *Support Cancer Care* 403.
- Craig, G.M., 'On withholding artificial hydration and nutrition from terminally ill sedated patients. The debate continues' (1996) 22(3) *Journal of Medical Ethics* 147.
- Cremer, R., Graftieaux, J.P., Renault, A., Le Gall, G., Haddad, L., and Dreyfuss, D., «Le consultant pour les limitations et les arrêts de traitement en réanimation» (2012) 4 *Reanimation* 231.

- Currow, D.C., 'Prescribing in palliative care as death approaches' (2007) 55(4) *J Am Geriatr Soc* 590.
- Dalal, S., Del Fabbro, E., and Bruera, E., 'Is there a role for hydration at the end of life?' (2009) 3(1) *Current Opinion in Supportive and Palliative Care* 72.
- Dany, L., Baumstarck, K., Dudoit, E., Duffaud, F., Auquier, P., and Salas, S., 'Determinants of favourable opinions about euthanasia in a sample of French physicians' (2015) 14 *BMC Palliative Care* 59.
- Davis, M.P., and Ford, P.A., 'Palliative sedation definition, practice, outcomes, and ethics' (2005) 8(4) *Journal of Palliative Medicine* 699.
- Davison, S.N., and Ferro, C.J., 'Management of pain in chronic kidney disease' (2009) 17(4) *Progress in Palliative Care* 186.
- de Graeff, A., 'De rol van consultatie bij palliatieve sedatie in de region Middenederland' (2008) 152 *Ned Tijdschr Geneesk* 2346.
- de Graeff, A., and Dean, M., 'Palliative sedation therapy in the last weeks in life: a literature review and recommendations for standards' (2007) 10 *Journal of Palliative Medicine* 67.
- de Graeff, A., Besse, T.C., and Krol, R.J.A., 'Pain' (Integraal Kankercentrum Nederland 2016).
- de Graeff, A., Molenkamp C.M., and Hesselmann, G.M., 'Nausea and Vomiting' (Integraal Kankercentrum Nederland 2014).
- De Haan, J., 'The new Dutch law on euthanasia' (2002) *Medical Law Review* 57.
- de Nonneville, A., Marin, A., Chabal, T., Tuzzolino, V., Fichaux, M., and Salas, S., 'End-of-life practices in France under the Claeys-Leonetti Law: report of three cases in the Oncology Unit' (2016) 9(3) *Case Reports in Oncology* 650.
- De Vries, U., 'Can a legal right to euthanasia exist? A Dutch perspective on a universal medico-ethical dilemma' (2003) 9(1) *Medico-Legal Journal of Ireland* 24.
- de Vaan, M., *Etymological Dictionary of Latin and the other Italic Languages* (Brill 2008).
- Dean, A., and Beard, B., 'Is sedation at the end of life compatible with the principles of palliative care?' (2015) 5 *End of Life Care Journal* e000001.
- Dean, M.M., Cellarius, V., Henry, B., and Oneschuk, D., 'Framework for continuous palliative sedation therapy in Canada' (2012) 15(8) *Journal of Palliative Medicine* 870.
- Delbecq, E., 'The Legal Permissibility of Continuous Deep Sedation at the End of Life: A Comparison of Laws and a Proposal' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Delbecq, H., 'Les soins palliatifs et l'accompagnement des malades en fin de vie' (Ministère des affaires sociales, de la santé et de la ville 1993).
- Deliens, L., Mortier, F., Bilsen, J., Cosyns, M., Vander Stichele, R., Vanoverloop, J., and Ingels, K., 'End-of-life decisions in medical practice in Flanders, Belgium: A nationwide survey' (2000) 356 *The Lancet* 1806.
- Department for Constitutional Affairs, 'Mental Capacity Act 2005: Code of Practice' (The Stationary Office 2007).
- Department of Health, 'End of Life Care Strategy: Promoting high quality care for all adults at the end of life' (Department of Health 2008).
- Department of Health, 'NHS Constitution for England' (Department of Health 2015).
- Department of Health, 'Our Commitment to You for End of Life Care: The Government Response to the Review of Choice in End of Life Care' (Department of Health 2016).
- Department of Health, 'Palliative Care For Children With Life-Limiting Conditions In Ireland – A National Policy' (DOH 2010).
- Department of Health, 'The Cancer Control Strategy' (DOH 2006).

- Department of Health, *'The National Cancer Strategy'* (DOH 1996).
- Department of Health, *'The National Positive Ageing Strategy'* (DOH 2013).
- Department of Health, *'The Primary Care Strategy'* (DOH 2001).
- Department of Health, Social Services and Public Safety, *'Living Matters, Dying Matters'* (Department of Health, Social Services and Public Safety 2010).
- Department of Health and Children, *'Report of the National Advisory Committee on Palliative Care'* (Department of Health and Children 2001).
- Devlin, P., *Easing the Passing* (The Bodley Head 1985).
- Dickenson, B., 'Cross-cultural issues in European bioethics' (1999) 913 *Bioethics* 249.
- Dixon, J., King, D., Matosevic, T., Clark, M., and Knapp, M., *'Equity in the Provision of Palliative Care in the UK: Review of Evidence'* (London School of Economics 2015).
- Donnelly, M., 'Capacity assessment under the Mental Capacity Act 2005: delivering on the functional approach?' (2009) 29 *Legal Studies* 464.
- Donnelly, M., *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press 2011).
- Donnelly, M., and Murray, C., (eds) *Ethical and legal debates in Irish healthcare* (Manchester University Press 2016).
- Donnelly, S., and Purcell, S., 'The evolution of the law on assisted suicide in the United Kingdom and the possible implications for Ireland' (2009) 15(2) *Medico-Legal Journal of Ireland* 82.
- Douglas, C., Kerridge, I., and Ankeny, R., 'Managing intentions: the end-of-life administration of analgesics and sedatives, and the possibility of slow euthanasia' (2008) 22(7) *Bioethics* 388.
- Doyle, D., 'Palliative Medicine: the first 18 years of a new sub-specialty of General Medicine' (2005) 35 *Journal of the Royal College of Physicians* 199.
- Dudzinski, D.M., 'The Principle of Double Effect in Palliative Care: Euthanasia by Another Name?' in van Norman, G.A., Jackson, S., Rosenbaum, S.H., and Palmer, S.K., *Clinical Ethics in Anesthesiology* (Cambridge University Press 2011).
- Dunet-Larousse, E., 'La loi du 4 mars 2002 et les soins palliatifs' (2003) 2 *Médecine Palliative* 259.
- Dunlop, R.J., Ellershaw, J.E., Baines, M.J., Sykes, N., and Saunders, C.M., 'On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far?: A reply' (1995) 21 *Journal of Medical Ethics* 141.
- Dworkin, R., *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom* (Harper Collins 1993).
- Dwyer, I., and McCarthy, J., 'Experiences of palliative care nurses in the utilization of palliative sedation in a hospice setting' (2016) 6 *End-of-Life Journal* 1.
- Dyer, C., 'Dying woman seeks backing to hasten death' (2007) 334(7589) *British Medical Journal* 329.
- Economist Intelligence Unit, *'Quality of Death Index'* (2nd edn, *The Economist* 2015).
- Ellershaw, J., and Wilkinson, S., (eds), *Care of the Dying: A Pathway to Excellence* (2nd edn, Oxford University Press 2011).
- Enck, R.E., 'Drug-induced terminal sedation for symptom control' (1991) 8 *American Journal of Hospice and Palliative Care* 2.
- European Association of Palliative Care, 'White Paper on standards and norms for hospice and palliative care in Europe: part 2' (2010) 17(1) *European Journal of Palliative Care* 22.
- European Declaration on Palliative Care* (2014).
- Eurostat, *'People in the EU: who are we and how do we live?'* (Publications Office of the European Union 2015).

- Evans, M.J., and Hallett, C.E., 'Living with dying: a hermeneutic phenomenological study of the work of hospice nurses' (2007) 16(4) *Journal of Clinical Nursing* 742.
- Feldman, D., 'Human dignity as a legal value: Part 1' (1999) *Public Law* 682.
- Feldman, D., 'Human dignity as a legal value: Part 2' (2000) *Public Law* 61.
- Ferrand, E., Dreyfus, J.F., Chastrusse, M., Ellien, F., Lemaire, F., and Fischler, M., 'L'évolution des demandes de mort anticipées exprimées auprès des équipes de soins palliatifs en France' (2012) 11(3) *Médecine Palliative* 121.
- Ferrand, E., Robert, R., Ingrand, P., and Lemaire, F., 'Withholding and withdrawal of life support in intensive-care units in France: a prospective survey' (2001) 357(9249) *Lancet* 9.
- Field, D., and Addington-Hall, J., 'Extending specialist palliative care to all?' (1999) 48 *Social Science and Medicine* 1271.
- Fink, M., 'France' in Gronemeyer, R., Fink, M., Globisch, M., and Schumann, F., *Helping People at the End of their Lives: Hospice and Palliative Care in Europe* (Lit Verlag 2007).
- Fins, J.J., and Nilson, E.G., 'Withholding and Withdrawing Life-Sustaining Care' in Hanks, G., Cherny, N.I., Christakis, N.A., Fallon, M., Kaasa, S., and Portenoy, R.K., (eds), *Oxford Textbook of Palliative Medicine* (4th edn, Oxford University Press 2011).
- Finucane, T.E., Christmas, C., and Travis, K., 'Tube feeding in patients with advanced dementia' (1999) 282(14) *Journal of the American Medical Association* 1365.
- Fohr, S.A., 'The double effect of pain medication: separating myth from reality' (1998) 1 (4) *Journal of Palliative Medicine* 315.
- Foster, C., *Human Dignity in Bioethics and Law* (Hart Publishing 2011).
- Foster, C., Herring, J., Melham, K., and Hope, T., 'The double effect effect' (2011) 20 *Cambridge Quarterly of Healthcare Ethics* 56.
- Fox, R.C., and Swazey, J.P., *Observing Bioethics* (Oxford University Press 2008).
- Francke, A.L., 'Palliative Care for Terminally Ill Patients in the Netherlands: Dutch Government Policy' (The Hague 2003).
- Fürst, C.J., and Hagenfeldt, K., 'End-of-life sedation: definition and clinical guidelines needed' (2002) 99(39) *Lakartidningen* 3830.
- Galvin, J., 'An audit of pressure ulcer incidence in a palliative care setting' (2002) 8(5) *International Journal of Palliative Nursing* 214.
- Gamondi, C., Larkin, P., and Payne, S., 'Core competencies in palliative care: an EAPC White Paper on palliative care education – part 1' (2013) 20(2) *European Journal of Palliative Care* 86.
- Garner, B.A., *Black's Law Dictionary* (9th edn, Thompson/West 2009).
- General Medical Council, 'Consent: Patients and Doctors Making Decisions Together' (General Medical Council 2008).
- General Medical Council, 'Good Medical Practice' (General Medical Council 2013).
- General Medical Council, 'Treatment and Care Towards the End of Life: Good Practice in Decision Making' (General Medical Council 2010).
- General Medical Council, 'Withholding and Withdrawing – Guidance for Doctors' (General Medical Council 2002).
- Gevers, S., 'Euthanasia: law and practice in The Netherlands' (1996) 52(2) *Br Med Bull* 326.
- Gevers, S., 'Terminal sedation: a new legal approach' (2003) 10 *European Journal of Health Law* 359.
- Gielen, J., Van den Branden, S., Van Iersel, T., and Broeckaert, B., 'Flemish palliative-care nurses' attitudes to palliative sedation: a quantitative study' (2012) 19 *Nursing Ethics* 692.
- Gilbert, J., 'Palliative medicine: a new specialty changes an old debate' (1996) 52(2) *Br Med Bull* 296.

- Gomes, B., and Higginson, I.J., 'Where people die (1974–2030): past trends, future projections and implications for care' (2008) 22(1) *Palliative Medicine* 33.
- Gomes, B., Calanzani, N., and Higginson, I.J., 'Reversal of the British trends in place of death: time series analysis 2004–2010' (2012) 26(2) *Palliative Medicine* 102.
- Good, P., Cavenagh, J., Mather, M., and Ravenscroft, P., '*Medically Assisted Hydration for Adult Palliative Care Patients*' (2008) 2Cochrane Database of Systematic Reviews.
- Good, P., Richard, R., Syrmis, W., Jenkins-Marsh, S., and Stephens, J., '*Medically Assisted Hydration for Adult Palliative Care Patients*' (2014) 4Cochrane Database of Systematic Reviews.
- Gordijn, B., and Janssens, R., 'Euthanasia and palliative care in the Netherlands: an analysis of the latest developments' (2004) 12(3) *Health Care Analysis* 195.
- Gott, M., Seymour, J.E., Ingleton, C., and Bellamy, G., "'That's part of everybody's job": the perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care' (2012) 26(3) *Palliative Medicine* 232.
- Griffiths, J., 'Assisted suicide in the Netherlands: the Chabot case' (1995) 58(2) *The Modern Law Review* 232.
- Gronemeyer, R., Fink, M., Globisch, M., and Schumann, F., *Helping People at the End of their Lives: Hospice and Palliative Care in Europe* (Lit Verlag 2005).
- Gross, H., *A Theory of Criminal Justice* (Oxford University Press 1979).
- Grosz, S., Beatson, J., and Duffy, P., *Human Rights: The 1998 Act and the European Convention* (Sweet and Maxwell 2000).
- Gruskin, S., Bogecho, D., and Ferguson, L., 'Rights-based approaches to health policies and programs: articulations, ambiguities, and assessment' (2010) 31(2) *Journal of Public Health Policy* 129.
- Gulland, A., 'French parliament passes law to allow sedation at end of life' (2016) *British Medical Journal* 352.
- Gury, J.P., *Compendium Theologiae Moralis* (5th edn, Ratisbon 1874).
- Gwyther, L., Brennan, F., and Harding, R., 'Advancing palliative care as a human right' (2009) 38(5) *Journal of Pain and Symptom Management* 767.
- Hamano, J., Morita, T., Fukui, S., Kizawa, Y., Tunetou, S., Shima, Y., Kobayakawa, M., Aoyama, M., and Miyashita, M., 'Trust in physicians, continuity and coordination of care, and quality of death in patients with advanced cancer' (2017) *Journal of Palliative Medicine* [ahead of print].
- Hanafin, P., *Last Rights: Death, Dying and the Law in Ireland* (Cork University Press 1997).
- Hanks, G.W., Conno, F., Cherny, N., Hanna, M., Kalso, E., McQuay, H.J., Mercadante, S., Meynadier, J., Poulain, P., Ripamonti, C., Radbruch, L., Casas, J.R., Sawe, J., Twycross, R.G., Ventafridda, V., 'Morphine and alternative opioids in cancer pain: the EAPC recommendations' (2001) 84(5) *Br J Cancer* 587.
- Harding, R., Beynon, T., Hodson, F., Coady, E., Kinirons, M., Selman, L., and Higginson, I., 'Provision of palliative care for chronic heart failure inpatients: how much do we need?' (2009) *BMC Palliative Care* 8.
- Harding, R., Easterbrook, P., Higginson, I.J., Karus, D., Raveis, V.H., and Marconi, K., 'Access and equity in HIV/AIDS palliative care: a review of the evidence and responses' (2005) 19(3) *Palliative Medicine* 251.
- Hasselaar, J.G., Verhagen, S.C., and Visser, K.C., 'When cancer symptoms cannot be controlled: the role of palliative sedation' (2009) 3 *Current Opinion in Supportive and Palliative Care* 14.

- Hasselaar, J.G.J., Verhagen, S., and Wolff, A.P., 'Changed patterns in Dutch palliative sedation practices after the introduction of a national guideline' (2009) 169(5) *Arch Intern Med* 430.
- Health Service Executive, *Palliative Care Services – Five Year/Medium Term Development Framework* (Health Service Executive 2009).
- Helme, T., and Padfield, N., 'Setting euthanasia on the level' (1993) 15 *Liverpool Law Review* 75.
- Hennette-Vaucher, S., 'France' in Griffiths, J., Weyers, H., and Adams, M., *Euthanasia and Law in Europe* (Bloomsbury 2008).
- Herberg, J., and Pievsky, D., 'Article 3: Prohibition of Torture and of Inhuman or Degrading Treatment' in Lord Lester Herne Hill, Pannick, D., and Herberg, J., (eds), *Human Rights Law and Practice* (2nd edn, LexisNexis 2004).
- Herring, J., *Criminal Law: Texts, Cases, and Materials* (2nd edn, Oxford University Press 2012).
- Higginson, I.J., and Sen-Gupta, G.J., 'Place of care in advanced cancer: a qualitative systematic literature review of patient preferences' (2000) 3(3) *Journal of Palliative Medicine* 287.
- Higginson, I.J., and Wilkinson, S., 'Marie Curie nurses: enabling patients with cancer to die at home' (2002) 7(5) *British Journal of Community Nursing* 240.
- Hilden, H.M., and Honkasalo, M.L., 'Finnish nurses' interpretations of patient autonomy in the context of end-of-life decision-making' (2006) 13(1) *Nursing Ethics* 41.
- Hirsch, E., *Mort par sedation: Une nouvelle éthique du «bien mourir»?* (Erès 2016).
- Hollande, F., *Le Changement c'est Maintenant: Mes 60 Engagements pour la France*
- Holm, S., 'Terminal Sedation and Euthanasia: The Virtue in Calling a Spade What It Is' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Holmes, H.H., Hayley, D.C., Alexander, G.C., and Sachs, G.A., 'Reconsidering medication appropriateness for patients late in life' (2006) 166(6) *Arch Intern Med* 605.
- Hope, T., *Medical Ethics: A Very Short Introduction* (Oxford University Press 2004).
- Horn, R., 'Advance directives in English and French law: different concepts, different values, different societies' (2014) 22(1) *Health Care Analysis* 59.
- Horn, R., 'Euthanasia and end-of-life practices in France and Germany: a comparative study' (2013) 16(2) *Medicine, Health Care and Philosophy* 197.
- Horn, R., "I don't need my patients' opinion to withdraw treatment": patient preferences at the end-of-life and physician attitudes towards advance directives in England and France' (2014) 17(3) *Medicine, Health Care, and Philosophy* 425.
- House of Commons Health Committee, *End of Life Care: Fifth Report of Session 2014–15* (HC 805).
- House of Commons Public Administration and Constitutional Affairs Committee, *Follow-up to PHSO Report: Dying without dignity* (HC432).
- House of Lords, *Report of the House of Lords Select Committee on Medical Ethics* (Paper 21-21 of 1993–1994).
- Houses of the Oireachtas Joint Committee on Health and Children, *Report on End of Life and Palliative Care in Ireland* (July 2014).
- Howard, R.A., 'The Calman–Hine report: a personal retrospective on the UK's first comprehensive policy on cancer services' (2006) 7(4) *The Lancet Oncology* 336.
- Hull, M.A., Rawlings, J., Field, J., Allision, S.P., Murray, F.E., McIntyre, A.S., Mahida, Y.R., and Hawkey, C.J., 'Audit of outcome of long-term enteral nutrition by percutaneous endoscopic gastrostomy' (1993) 341 *Lancet* 869.

- Human Rights Watch, 'Global State of Pain Treatment: Access to Medicines and Palliative Care' (Human Rights Watch 2011).
- Huxtable, R., *Euthanasia, Ethics and the Law: From Conflict to Compromise* (Routledge-Cavendish 2007).
- Huxtable, R., 'Whatever you want? Beyond the patient in medical law' (2008) 16(3) *Health Care Analysis* 288.
- Huxtable, R., and Horn, R., 'Continuous Deep Sedation at the End of Life: Balancing Benefits and Harms in England, Germany and France' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Hynson, J.L., and Sawyer, S.M., 'Paediatric palliative care: distinctive needs and emerging issues' (2001) 37(4) *Journal of Paediatrics and Child Health* 323.
- Hynson, J.L., Gillis, J., Collins, J.J., Irving, H., and Trethewie, S.J., 'The dying child: how is care different?' (2003) 179 (6 Suppl) *Med J Aust* S20.
- Independent Review of the Liverpool Care Pathway, 'More Care: Less Pathway: A Review of the Liverpool Care Pathway' (2013).
- International Association for Hospice and Palliative Care, 'The Declaration of Venice: palliative care research in developing countries' (2007) 21(1) *Journal of Pain and Palliative Care Pharmacotherapy* 31.
- International Association for Hospice and Palliative Care, and Worldwide Palliative Care Alliance, 'Joint Declaration and Statement of Commitment on Palliative Care and Pain Treatment as Human Rights' (2008) 22(4) *Journal of Pain and Palliative Care Pharmacotherapy* 300.
- International Children's Palliative Care Network, 'Mumbai Declaration' (2014).
- Irish Association of Palliative Care, 'Artificial Hydration in Terminally Ill Patients' (Irish Association of Palliative Care 2011).
- Irish Association of Palliative Care, 'Palliative Sedation' (Irish Association of Palliative Care 2011).
- Irish Association of Palliative Care, 'Voluntary Euthanasia' (Irish Association of Palliative Care 2011).
- Irish Hospice Foundation, 'Access to Specialist Palliative Care Services and Place of Death in Ireland' (Irish Hospice Foundation 2013).
- Irish Hospice Foundation, 'Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks' (Irish Hospice Foundation 2008).
- Irish Hospice Foundation, 'A Baseline Study on the Provision of Hospice/Specialist Palliative Care Services in Ireland' (IHF 2006).
- Irish Hospice Foundation, 'Access to Specialist Palliative Care Services and Place of Death in Ireland' (IHF 2013).
- Irish Hospice Foundation, 'Primary Palliative Care in Ireland' (Irish Hospice Foundation 2011).
- Irish Hospice Foundation, 'Strategic Plan: 2012–2015' (Irish Hospice Foundation 2012).
- Irish Hospice Foundation, and Health Service Executive, 'Palliative Care for All: Integrating Palliative Care into Disease Management Frameworks' (IHF 2008).
- Irish Human Rights Commission, 'Making Economic, Social and Cultural Rights Effective' (Dublin 2005).
- Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (3rd edn, Dublin 1989).
- Irish Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (4th edn, Dublin 1994).

- Irish Medical Council, *'Constitution and Functions: A Guide to Ethical Conduct and Behaviour and to Fitness to Practise'* (2nd edn, Dublin 1984).
- Irish Medical Council, *'Guide to Professional Conduct and Ethics for Registered Medical Practitioners'* (8th edn, Dublin 2016).
- Issaka, R.B., Shapiro, D.M., Parikh, N.D., Mulcahy, M.F., Komanduri, S., Martin, J.A., and Keswani, R.N., 'Palliative venting percutaneous endoscopic gastrostomy tube is safe and effective in patients with malignant obstruction' (2013) 28(5) *Surgical Endoscopy* 1669.
- Ivone, V. 'Access to Palliative Care in the Italian Legal System' in Negri, S., Taupitz, J., Salkić, A., and Zwick, A. (eds) *Advance Care Decision Making in Germany and Italy: A Comparative, European and International Law Perspective* (Springer 2013).
- Jaarsma T., Beattie J.M., Ryder, M., Rutten, F.H., McDonagh, T., Mohacsi, P., Murray, S. A., Grodzicki, T., Bergh, I., Metra, M., Ekman, I., Angermann, C., Leventhal, M., Pitsis, A., Anker, S.D., Gavazzi, A., Ponikowski, P., Dickstein, K., Delacretaz, E., Blue, L., Strasser, F., and McMurray, J., 'Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology' (2009) 11(5) *European Journal of Heart Failure* 433.
- Jackson, E., and Keown, J., *Debating Euthanasia* (Hart Publishing 2012).
- Jackson, W.C., 'Palliative sedation vs. terminal sedation: what's in a name?' (2002) 19 *American Journal of Hospice Palliative Care* 81.
- Jacobson, N., 'A taxonomy of dignity: a grounded theory study' (2009) 9(3) *BMC International Health and Human Rights*.
- Jansen, L.A., 'Disambiguating clinical intentions: the ethics of palliative sedation' (2010) 35 *Journal of Medicine and Philosophy* 19.
- Jansen, L.A., and Sulmasy, D.P., 'Sedation, alimentation, hydration, and equivocation: careful conversation about care at the end of life' (2002) 136(11) *American College of Physicians-American Society of Internal Medicine* 845.
- Janssens, R., *Palliative Care: Concepts and Ethics* (Nijmegen University Press 2001).
- Janssens, R., van Delden, J.J., and Widdershoven, G.A., 'Palliative sedation: not just normal medical practice. Ethics reflections on the Royal Dutch Medical Association's guideline on palliative sedation' (2012) 38(11) *Journal of Medical Ethics* 664.
- Janssens, R.J.P.A., and ten Have, H., 'The concept of palliative care in the Netherlands' (2001) 15 *Palliative Medicine* 481.
- Janssens, R.J.P.A., ten Have, H., and Zylicz, Z., 'Hospice and euthanasia in the Netherlands: an ethical point of view' (1999) 25(5) *Journal of Medical Ethics* 408.
- Janssens, R.M., Olthuis, G., Dekkers, W., 'Terminal sedation and dehydration go hand in hand' (2005) 11(7) *International Journal of Palliative Nursing* 334.
- Johnston, B., Larkin, P., Connolly, M., Barry C., Narayanasamy, M., Östlund, U., and McIlfratrick, S., 'Dignity-conserving care in palliative care settings: an integrative review' (2015) 24(13–14) *Journal of Clinical Nursing* 1743.
- Johnston, C., 'Advance decision-making – rhetoric or reality?' (2014) 34(3) *Legal Studies* 497.
- Jones, D.A., 'Death by Equivocation: A Manifold Definition of Terminal Sedation' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Jones, D.A., Gastmans, C., and MacKellar, C., (eds) *Euthanasia and Assisted Suicide: Lessons from Belgium* (Cambridge University Press 2017).
- Juth, N., Lindblad, A., Lynöe, N., Sjöstrand, M., and Helgesson, G., 'European Association for Palliative Care (EAPC) framework for palliative sedation: an ethical discussion' (2010) 9(20) *BMC Palliative Care*.

- Kaasa, S., and Loge, J.H., 'Quality of life in palliative care: principles and practice' (2003) 17(1) *Palliative Medicine* 11.
- Kamm, F., 'Physician-assisted suicide: the doctrine of double effect, and the ground of value' (1999) 109(3) *Ethics* 602.
- Keane, E., 'Withdrawal of life support for patients in PVS' (2011) 17(2) *Medico-Legal Journal of Ireland* 83.
- Kelley, A., Fischberg, D.J., and Morrison, R.S., 'Palliative Care in Hospitals' in Cohen, J., and Deliens, L., *A Public Health Perspective on End of Life Care* (Oxford University Press 2012).
- Keown, J., *Euthanasia, Ethics and Public Policy* (Cambridge University Press 2002).
- Kirk, T.W., Mahon, M.M., and Palliative Sedation Task Force of the National Hospice and Palliative Care Organization Ethics Committee, 'National Hospice and Palliative Care Organization (NHPCO) Position Statement and Commentary on the Use of Palliative Sedation in Imminently Dying Terminally Ill Patients' (2010) 39(5) *Journal of Pain and Symptom Management* 914.
- Klepstad, P., Kaasa, S., Cherny, N., Hanks, G., de Conno, F., 'Pain and pain treatments in European palliative care units. A cross sectional survey from the European Association for Palliative Care Research Network' (2005) 19 *Palliative Medicine* 477.
- Ko, D.N., and Blinderman, C.D., 'Withholding and Withdrawing Life-Sustaining Treatment (Including Artificial Nutrition and Hydration)' in Cherny, N., Fallon, M., Kaasa, S., Portenoy, R.K., and Currow, D.C., (eds) *Oxford Textbook of Palliative Medicine* (5th edn, Oxford University Press 2015).
- Koffman, J., and Higginson, I.J., 'Dying to be home? Preferred location of death of first-generation black Caribbean and native-born white patients in the United Kingdom' (2004) 7(5) *Journal of Palliative Medicine* 628.
- Korea Declaration on Hospice and Palliative Care (March 2005).
- Krakauer, E.L., and Quinn, T.E., 'Sedation in Palliative Medicine' in Hanks, G., Cherny, N.I., Christakis, N.A., Fallon, M., Kaasa, S., and Portenoy, R.K., (eds), *Oxford Textbook of Palliative Medicine* (4th edn, Oxford University Press 2011).
- Kübler-Ross, E., *On Death and Dying* (Tavistock 1969).
- Kuhse, H., *The Sanctity-of-Life Doctrine in Medicine: A Critique* (Clarendon Press 1987).
- «La loi sur la fin de vie votée à l'Assemblée» *Le Monde* (Paris, 17 March 2015) <http://www.lemonde.fr/fin-de-vie/article/2015/03/17/l-assemblee-vote-aujourd-hui-la-loi-sur-la-fin-de-vie_4595401_1655257.html> (accessed 4 September 2017).
- Lagerway, W., (tr), 'Euthanasia Case Leeuwarden – 1973' (1988) 3 *Issues in Law and Medicine* 439.
- Lalande, F., and Veber, O., 'La mort à l'hôpital' (Inspection Générale des affaires sociales 2010).
- Lancaster, H., Finlay, I., Downman, M., and Dumas, J., 'Commissioning of specialist palliative care services in England' *British Medical Journal* [online first] 28 February 2017.
- Landa, M., «Un droit» *Le Monde* (17 November 1979).
- Lanham, D., 'Larsonneur revisited' (1976) *Criminal Law Review* 276.
- Lanza, M.L., 'Nurses as patient assault victims: An update, synthesis, and recommendations' (1992) 6(3) *Archives of Psychiatric Nursing* 163.
- Larkin, P.J., Sykes, N.P., Centeno, C., Ellershaw J.E., Elsner, F., Eugene, B., Gootjes, J.R., Nabal, M., Noguera, A., Ripamonti, C., Zucco, F., and Zuurmond, W.W., 'The management of constipation in palliative care: clinical practice recommendations' (2008) 22(7) *Palliative Medicine* 796.

236 Bibliography

- Laurance, J., 'Woman goes to court in historic euthanasia case' *Independent* (13 February 2007).
- Law Reform Commission, *Report on Homicide: Murder and Involuntary Manslaughter* (LRC87–2008).
- Le, B.H., and Watt, J.N., 'Care of the dying in Australia's busiest hospital' (2010) 13(7) *Journal of Palliative Medicine* 855.
- Leadership Alliance for the Care of Dying People, '*One Chance to get it Right*' (LACDP 2014).
- Leavens, M.E., Stratton Hill, C., Cech, D.A., and Weyland, J.B., 'Intrathecal and intraventricular morphine for pain in cancer patients: initial study' (1982) 56 *J Neurosurg* 241.
- Legemaate, J., 'The Dutch National Guideline on Palliative Sedation' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Legemaate, J., Verkerk, M., van Wijlick, E., and de Graeff, A., 'Palliative sedation in the Netherlands: starting-points and contents of a national guideline' (2007) 14 *European Journal of Health Law* 61.
- Leichsenring, K., Billings, J., and Nies, H., (eds), *Long-term Care in Europe: Improving Policy and Practice* (Palgrave Macmillan 2013).
- Leonetti, J., '*Respecter la vie, Accepter la mort*' Report N° 1708 fait au nom de la mission d'information sur l'accompagnement de la fin de vie 2004.
- Lesieur, O., Leloup, M., Gonzalez, F., and Mamzer, M.F., 'Withholding or withdrawal of treatment under French rules: a study performed in 43 intensive care units' (2015) 5 *Annals of Intensive Care* 15.
- Letter from Manfred Nowak, Special Rapporteur on Torture, and Anand Grover, Special Rapporteur on the right to the highest attainable standard of health, to Her Excellency Ms. Selma Ashipala-Musavyi, Chairperson of the 52nd Session of the Commission on Narcotic Drugs, Ref G/SO 214(53–21)* (10 December 2008).
- Lindley, R., *Autonomy* (Macmillan Education 1986).
- Lombard, J., 'Sedation of the terminally ill patient: the role of the doctrine of double effect' (2015) 21(1) *Medico-Legal Journal of Ireland* 22.
- Lucknow Declaration/Palliative Care Declaration* (2011).
- Lynch, T., Connor, S., and Clark, D., 'Mapping levels of palliative care development: a global update' (2013) 45(6) *Journal of Pain and Symptom Management* 1094.
- Macklin, R., 'Dignity is a useless concept' (2003) 327 *British Medical Journal* 1419.
- MacManus, D., and Zylicz, Z., 'Implementing Mental Capacity Act in the everyday decisions of the hospice multi-disciplinary team' (2008) 7(3) *Advances in Palliative Medicine* 115.
- Madden, D., *Medicine, Ethics and the Law* (3rd edn, Bloomsbury Professional 2016).
- Madden Report on Post Mortem Practice and Procedures* (Department of Health and Children 2006).
- Maltoni, M., Pittureri, C., Scarpi, E., Piccinini, L., Martini, F., Turci, P., Montanari, L., Nanni, O., and Amadori, D., 'Palliative sedation therapy does not hasten death: results from a prospective multicenter study' (2009) 20 *Annals of Oncology* 1163.
- Maltoni, M., Scarpi, E., and Nanni, O., 'Palliative sedation in end-of-life care' (2013) 25(4) *Curr Opin Oncol* 360.
- Mangan, J.T., '*An Historical Analysis of the Principle of Double Effect*' (1945) *Theological Studies* 41.
- Marcovitch H., (ed), *Black's Medical Dictionary* (41st edn, A & C Black Publishers 2005).

- Marchant J.R.V., and Charles, J.F., *Cassell's Latin Dictionary (Latin-English and English-Latin)* (Cassell and Company 1948).
- Marquis, D.B., 'Four versions of double effect' (1991) 16 *The Journal of Medicine and Philosophy* 515.
- Mason, J.K., and Laurie, G., *Mason & Mccall Smith's Law & Medical Ethics* (8th edn, Oxford University Press 2011).
- Mason, J.K., and Laurie, G.T., *Mason & McCall Smith's Law & Medical Ethics* (9th edn, Oxford University Press 2013).
- Materstvedt, L.J., Clark, D., Ellershaw, J., Førde, R., Gravgaard, A.M., Müller-Busch, H. C., Porta i Sales, J., and Rapin, C.H., 'Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force' (2003) 17 *Palliative Medicine* 97.
- Mazoyer, J., Sastre, M.T.M., Sorum, P.C., and Mullet, E., 'French laypeople's and health professionals' views on the acceptability of terminal sedation' (2016) 42 *Journal of Medical Ethics* 627.
- McCaffrey, M., *Nursing Practice Theories Related to Cognition, Bodily Pain, and Man-environment Interactions* (UCLA Students' Store 1968).
- McCarron, M., Higgins, A., Larkin, P., Drennan, J., McCallion, P., Payne, S., Hynes, G., and May, P., *Evaluation of the Programme to Support Palliative and Hospice Care in the Republic of Ireland* (Atlantic Philanthropies 2013).
- McCarthy, K., *A Dream Unfolding: Portrait of St Patrick's Hospital & Marymount Hospice* (St Patrick's Hospital/Marymount Hospice 2004).
- McCrudden, C., 'Human dignity and judicial interpretation of human rights' (2008) 19(4) *The European Journal of International Law* 655.
- McKeown, K., 'Key Performance Indicators for End-of-Life Care: A Review of Data on Place of Care and Place of Death in Ireland' (Irish Hospice Foundation, 2012).
- McKeown, K., Haase, T., and Twomey, S., *Dying in Hospital in Ireland: Nurse and Doctor Perspectives, Report 2* (Irish Hospice Foundation 2010).
- McKeown, K., Haase, K., and Twomey, S., *Resources and Facilities for End of Life Care in Hospitals in Ireland* (Irish Hospice Foundation 2010).
- McLean, S., *Assisted Dying: Reflections on the need for Law Reform* (Routledge 2007).
- McQuay, H., 'Opioids in pain management' (1999) 353 *Lancet* 2229.
- Mecussen, K., Bossuyt, N., Bilsen, J., Echteld, M., Van Casteren, V., Deliens, L., 'GPs' awareness of patients' preference for place of death' 200959(566) *British Journal of General Practice* 665.
- Miccinesi, G., Rietjens, J.A.C., Deliens, L., Paci, E., Bosshard, G., Nilstun, T., Norup, M., and van der Wal, G., 'Continuous deep sedation: physicians' experiences in six European countries' (2006) 31(2) *Journal of Pain and Symptom Management* 122.
- Milićević, N., 'The hospice movement: History and current worldwide situation' (2002) 10(1) *Archive of Oncology* 29.
- Mill, J.S., *On Liberty* (JW Parker and Son 1859).
- Miller, S.C., Lima, J., Gozalo, P.L., and Mor, V., 'The growth of hospice care in U.S. nursing homes' (2010) 58(8) *Journal of the American Geriatric Society* 1481.
- Mino, J.C., and Mollard, J.M., 'The Organisation of Palliative Care in France' in Ahmedzai, S.H., Gómez-Batiste, X., Engels, Y., Hasselcar, J., Jaspers, B., Leppert, W., Menten, J., Mollard, J.M., and Vissers, K., (eds) *Assessing Organisations to Improve Palliative Care in Europe* (Vantilt Publishers 2010).
- Montreal Declaration on Hospice and Palliative Care* (2014).
- Morita, T., 'Palliative sedation to relieve psycho-existential suffering of terminally ill cancer patients' (2004) 28 *Journal of Pain Symptom Management* 445.

- Morita, T., Hyodo, I., Yoshimi, T., Ikenaga, M., Tamura, Y., Yoshizawa, A., Shimada, A., Akechi, T., Miyashita, M., Adachi, I., 'Association between hydration volume and symptoms in terminally ill cancer patients with abdominal malignancies' (2005) 16(4) *Annals of Oncology* 640.
- Morita, T., Imai, K., Yokomichi, N., Mori, M., Kizawa, Y., and Tsuneto, S., 'Continuous deep sedation: a proposal for performing more rigorous empirical research' (2017) 53(1) *Journal of Pain and Symptom Management* 146.
- Morita, T., TeiY., and Inoue, S., 'Impaired communication capacity and agitated delirium in the final week of terminally ill cancer patients: prevalence and identification of research focus' (2003) 26(3) *Journal of Pain and Symptom Management* 827.
- Morita, T., Tsuneto, S., and Shima, Y., 'Definition of sedation for symptom relief: a systematic literature review and a proposal of operational criteria' (2002) 24(4) *Journal of Pain and Symptom Management* 447.
- Morita, T., Tsunoda, J., Inoue, S., and Chihara, S., 'Terminal sedation for existential distress' (2000) 17 *American Journal of Hospice Palliative Care* 189.
- Morris, D., 'Assisted suicide under the European Convention on Human Rights: a critique' (2003) *European Human Rights Law Review* 65.
- Mount, B.M., 'Morphine drips, terminal sedation, and slow euthanasia: definitions and facts, not anecdotes' (1996) 12 *Journal of Palliative Care* 31.
- Mpanga Sebuyira, L., Mwangi-Powell, F., Pereira, J., and Spence, C., 'The Cape Town Palliative Care Declaration: home-grown solutions for Sub-Saharan Africa' (2003) 6(3) *Journal of Palliative Medicine* 341.
- Murray, S.A., Boyd, K., and Sheikh, A., 'Developing primary palliative care' (2005) 330 (7492) *British Medical Journal* 671.
- Murtagh, F.E.M., 'Patterns of dying: palliative care for non-malignant disease' (2004) 4(1) *Clinical Medicine* 39.
- Nambisan, V., 'Providing evidence of intention when giving palliative sedation' (2012) 19(1) *European Journal of Palliative Care* 93.
- National Audit Office, 'End of Life Care' (HC1043 Report by the Comptroller and Auditor and General, The Stationery Office 2008).
- National Council for Palliative Care, 'The Mental Capacity Act in Practice: Guidance for End of Life Care' (March 2008).
- National Council on Ageing and Older People, 'End-of-Life Care for Older People in Acute and Long-Stay Care Settings in Ireland' (National Council on Ageing and Older People 2008).
- National Ethics Committee, Veterans Health Administration, 'The ethics of palliative sedation as a therapy of last resort' (2007) 23(6) *American Journal of Hospice and Palliative Medicine* 483.
- National Palliative and End of Life Care Partnership, 'Ambitions for Palliative and End of Life Care' (2015).
- Needham, I., Aberhalden, C., Halfens, R.J., Fischer, J.E., and Dassen, T., 'Non-somatic effects of patient aggression on nurses: a systematic review' (2005) 49(3) *Journal of Advanced Nursing* 283.
- Negri, S. 'Universal Human Rights and End-of-Life Care' in Negri, S., Taupitz, J., Salkić, A., and Zwick, A. (eds) *Advance Care Decision Making in Germany and Italy: A Comparative, European and International Law Perspective* (Springer 2013).
- Negri, S., Taupitz, J., Salkić, A., and Zwick, A. (eds) *Advance Care Decision Making in Germany and Italy: A Comparative, European and International Law Perspective* (Springer 2013).

- Netherlands Programme for Palliative Care, 'NPTN: palliative care comes under the spotlight in the Netherlands' (2009) 16(3) *European Journal of Palliative Care* 15.
- NHS, 'The NHS Cancer Plan' (Department of Health 2000).
- NHS Clinical Commissioners, 'About CCGs' <<https://www.nhs.uk/our-organisation/clinical-commissioning/about-ccgs/>> accessed 3 November 2017.
- NHS England, 'Commissioning Person Centred End of Life Care: A Toolkit for Health and Social Care' (NHS 2016).
- NHS Scotland, 'Living and Dying Well: A National Action Plan for End of Life Care in Scotland' (The Scottish Government 2008).
- NHS Wales, 'Palliative and End of Life Care Delivery Plan' (March 2017).
- NHS Wales, 'Together for Health, Delivering End of Life Care' (NHS Wales Health Board 2013).
- NICE, 'Care of Dying Adults in the Last Days of Life' (NICE 2015).
- NICE, 'How NICE Clinical Guidelines are Developed: An Overview for Stakeholders, the Public and the NHS' (NICE 2012).
- NICE, 'Improving Supportive and Palliative Care for Adults with Cancer' (NICE 2004).
- NICE, 'Palliative Care for Adults: Strong Opioids for Pain Relief' (NICE 2016).
- Nilsson, J., Blomberg, C., Holgersson, G., Carlsson, T., Bergqvist, M., and Bergström, S., 'End-of-life care: Where do cancer patients want to die? A systematic review' (2017) *Asia-Pacific Journal of Clinical Oncology* [epub ahead of print].
- Nursing and Midwifery Board of Ireland, 'Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives' (October 2013).
- Nursing and Midwifery Board of Ireland, 'Collaborative Practice Agreement for Nurses and Midwives with Prescriptive Authority' (4th edn, NMBI 2016).
- Nursing and Midwifery Board of Ireland, 'The Code of Professional Conduct and Ethics for Registered Nurses and Registered Midwives' (NMBI 2014).
- Nursing and Midwifery Board of Ireland, 'Professional Guidance for Nurses Working with Older People' (2nd edn, November 2015).
- O'Connor, R., 'Physician-assisted suicide: the way forward?' (2004) 22 *Irish Law Times* 182.
- O'Hanlon, S., and Schweppe, J., 'Health, dignity and human rights' (2010) 11(2) *Medico-Legal Journal of Ireland* 97.
- O'Leary, N., and Tiernan, E., 'Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers' (2008) *Palliative Medicine* 77.
- O'Mahony, C., 'There is no such thing as a right to dignity' (2012) 10 *International Journal of Constitutional Law* 551.
- O'Morain, P., 'The Irish Hospice Foundation 1986–2006: The First 20 Years' (Irish Hospice Foundation 2006).
- O'Neill, B., and Fallon, M., 'ABC of palliative care: principles of palliative care and pain control' (1997) 315(7111) *British Medical Journal* 801.
- O'Neill, O., *Autonomy and Trust in Bioethics* (Cambridge University Press 2002).
- O'Shea, E., Murphy, K., Larkin, P., Payne, S., Froggatt, K., Casey, D., Ní Léime, A., and Keys, M., *End-of-Life Care for Older People in Acute and Long-Care Stay Settings in Ireland* (IHF 2008).
- O'Sioráin, L., Keegan, O., and McCormack, J., 'The Voluntary Sector' in Ling, J., and O'Sioráin, L., (eds), *Palliative Care in Ireland* (Open University Press 2005).
- Office for National Statistics, 'Cancer Registration Statistics, England: 2014' (ONS 2016).
- Office for National Statistics, 'National Population Projections: 2014-based Statistical Bulletin' (ONS 2015).

- Office of the High Commissioner for Human Rights, 'CESCR General Comment No. 14: *The Right to the Highest Attainable Standard of Health*' (11 August 2000).
- Oliver, D., 'Palliative care for Motor Neurone Disease' (2002) 2 *Practical Neurology* 68.
- Onwuteaka-Philipsen B.D., Brinkman-Stoppelenburg, A., Penning, C., de Jong-Krul, G.J., van Delden, J.J., van der Heide, A., 'Trends in end-of-life practices before and after the enactment of the euthanasia law in the Netherlands from 1990 to 2010: a repeated cross-sectional survey' (2012) 380(9845) *Lancet* 908.
- Orentlicher, D., 'The Supreme Court and physician-assisted suicide – rejecting assisted suicide but embracing euthanasia' (1997) 337 *The N Engl J Med* 1236.
- Ost, S., 'Euthanasia and the defence of necessity: advocating a more appropriate legal response' (2005) *Criminal Law Review* 355.
- Otlowski, M., *Voluntary Euthanasia and the Common Law* (Oxford University Press 1997).
- Overy, C., and Tansey, E.M., (eds), *Palliative Medicine in the UK c.1970–2010* Wellcome Witnesses to Twentieth Century Medicine (University of London 2013).
- Palmer, S., 'AIDs, expulsion and Article 3 of the European Convention on Human Rights' (2005) 5 *European Human Rights Law Review* 533.
- Panama Proclamation – Proclamation of Pain Treatment and the Application of Palliative Care as Human Rights* (2008).
- Papavasiliou, E., Payne, S., and Brearley, S., 'Current debates on end-of-life sedation: an international expert elicitation study' (2014) 22(8) *Support Care Cancer* 2141.
- Parliamentary and Health Service Ombudsman, *'Dying Without Dignity'* (Parliamentary and Health Service Ombudsman 2015).
- Parse, R.M., 'Human dignity: a humanbecoming ethical phenomenon' (2010) 23(3) *Nursing Science Quarterly* 257.
- Pastrana, T., Jünger, S., Ostgathe, C., Elsner, F., and Radbruch, L., 'A matter of definition – key elements identified in a discourse analysis of definitions of palliative care' (2008) 22 *Palliative Medicine* 222.
- Patel, B., Gorawara-Bhat, R., Levine, S., and Shega, J.W., 'Nurses' attitudes and experiences surrounding palliative sedation: components for developing policy for nursing professionals' (2012) 15 *Journal of Palliative Medicine* 432.
- Paterson, R., and Aitken-Swan, J., 'Public opinion on cancer; a survey among women in the Manchester area' (1954) 23 *Lancet* 857.
- Payne, S., 'To supplant, supplement or support? Organisational issues for hospices' (1998) 46(11) *Social Science and Medicine* 1495.
- Peruselli, C., Di Giulio, P., Toscani, F., Gallucci, M., Brunelli, C., Costantini, M., Tamburini, M., Paci, E., Miccinesi, G., Addington-Hall, J.M., and Higginson, I.J., 'Home palliative care for terminal cancer patients: a survey on the final week of life' (1999) 13 *Palliative Medicine* 233.
- Pfund, R., and Fowler-Kerry, S., (eds) *Perspectives on Palliative Care for Children and Young People: A Global Discourse* (CRC Press 2010).
- Pinna, M.Á.C., Correas, M.Á.S., Posadas, R.S., Prado, M.E.A., Márquez, M., del P.R., Rojas, J.A.F., Martín, T.G., de Ayala, C.I., and López, M.P.V., '*Sedación en Cuidados Paliativos*' (SECPAL, 2005).
- Pinter, H., Godbert, G., and Astbury, A., (eds), *100 Poems by 100 Poets* (Methuen 1986).
- Pogge, T., 'Montréal Statement on the Human Right to Essential Medicines' (2007) 16(1) *Cambridge Quarterly of Healthcare Ethics* 97.
- Porta-Sales, J., 'Palliative Sedation: Clinical, Pharmacological and Practical Aspects' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).

- Portenoy, R.K., 'Morphine infusions at the end of life: the pitfalls in reasoning from anecdote' (1996) 12 *Journal of Palliative Care* 44.
- Pring, J.T., *The Oxford Dictionary of Modern Greek: Greek-English and English-Greek* (Doubleday 1986).
- Pringle, J., Johnston, B., and Buchanan, D., 'Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: a systematic review' (2015) 29(8) *Palliative Medicine* 675.
- Queneau, P., and Osterman, G., *Soulager la Douleur* (Éditions Odile Jacob 1998).
- Quill, T.E., 'The ambiguity of clinical intentions' (1993) 329(14) *The N Engl J Med* 1039.
- Quill, T.E., Dresser, R., and Brock, D.W., 'The rule of double effect: a critique of its role in end-of-life decision-making' (1997) 337 *N Engl J Med* 1768.
- Quill, T.E., Lo, B., and Brock, D.W., 'Palliative Options of Last Resort: A Comparison of voluntary Stopping Eating and Drinking, Terminal Sedation, Physician-Assisted Suicide, and Voluntary Active Euthanasia' in Tännsjö, T., (ed), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004).
- Quill, T.E., Lo, B., Brock, D.W., and Meisel, A., 'Last-resort options for palliative sedation' (2009) 151(6) *Ann Intern Med* 421.
- Quinlan, C., and O'Neill, C., *Practitioners' Narrative Submissions* (IHF 2008).
- Quinn, W., 'Actions, Intentions, and Consequences: The Doctrine of Double Effect' in Quinn, W., *Morality and Action* (Cambridge University Press 1993).
- Rabeneck, L., Wray, N.P., and Petersen, N.J., 'Long-term outcomes of patients receiving percutaneous endoscopic gastrostomy tubes' (1996) 11 *J Gen Intern Med* 287.
- Rachels, J., 'Active and passive euthanasia' (1975) 292 *N Engl J Med* 78.
- Radbruch, L., Foley, K., De Lima, L., Prail, D., Fürst, C.J., 'The Budapest Commitments: setting the goals. A joint initiative by the European Association for Palliative Care, the International Association for Hospice and Palliative Care and Help the Hospice' (2007) 21 *Palliat Med* 269.
- Radbruch, L., Jünger, S., Payne, S., and Scholten, W., (eds) 'Access to Opioid Medication in Europe: Final report and Recommendations to the Ministries of Health' (November 2014).
- Radbruch, L., Payne, S., and EAPC Board of Directors, 'White Paper on standards and norms for hospice and palliative care in Europe: part 1' (2009) 16(6) *European Journal of Palliative Care* 278.
- Radbruch, L., Payne, S., and EAPC Board of Directors, 'White Paper on standards and norms for hospice and palliative care in Europe: part 2' (2010) 17(1) *European Journal of Palliative Care* 22.
- Radbruch, L., Payne, S., de Lima, L., and Lohmann, D., 'The Lisbon Challenge: acknowledging palliative care as a human right' (2013) 16(3) *Journal of Palliative Medicine* 301.
- Rady, M.Y., and Verheijde, J.L., 'Continuous deep sedation until death: palliation or physician-assisted death?' (2010) 27(3) *American Journal of Hospice and Palliative Medicine* 205.
- Raijmakers, N.J.H., van Zuylen, L., Costantini, M., Caraceni, A., Clark, J., Lundquist, G., Voltz, R., Ellershaw, J.E., van der Heide, A., 'Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects' (2011) 22 *Annals of Oncology* 1478.
- Randall, F., *The Mental Capacity Act: Implications for Palliative Care* (EAPC Congress, Vienna 2009).
- Randall, F., and Downie, R.S., *The Philosophy of Palliative Care: Critique and Reconstruction* (Oxford University Press 2006).

- Raus, K., Chambaere, K., and Sterckx, S., 'Controversies surrounding continuous deep sedation at the end of life: the parliamentary and societal debates in France' (2016) 17 *BMC Medical Ethics* 36.
- Raus, K., Sterckx, S., and Mortier, F., 'Can the Doctrine of Double Effect Justify Continuous Deep Sedation at the End of Life?' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Raus, K., Sterckx, S., and Mortier, F., 'Is continuous sedation at the end of life an ethically preferable alternative to physician-assisted suicide?' (2011) 11(6) *Am J Bioeth* 32.
- Raz, J., *The Authority of Law* (Oxford University Press 1979).
- Raz, J., *The Morality of Freedom* (Oxford University Press 1979).
- Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003.*
- Regan, S.L., Wittenberg-Lyles, E.M., Goldsmith, J., and Sanchez-Reilly, S., *Communication as Comfort: Multiple Voices in Palliative Care* (Taylor & Francis 2008).
- Regnard, C., 'The demise of the Liverpool Care Pathway: should we ban the highway code because of bad drivers?' (2014) 43(2) *Age Ageing* 171.
- Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Juan E. Méndez, A/HRC/22/53 (1 February 2013).*
- Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, 'Promotion and Protection of all Human Rights, Civil, Political, Economic, Social and Cultural Rights, including the Right to Development' A/HRC/10/44 (14 January 2009).*
- Reuzel, R.P., Hasselaar, G.J., Vissers, K.C., van der Wilt, G.J., Groenewoud, J.M., and Crul, B.J., 'Inappropriateness of using opioids for end-stage palliative sedation: a Dutch study' (2008) 22(5) *Palliative Medicine* 641.
- Rietjens, J., van Delden, J., Onwuteaka-Philipsen, B., Buiting, H., van der Maas, P., and van der Heide, A., 'Continuous deep sedation for patients nearing death in the Netherlands: descriptive study' (2008) 7648(336) *British Medical Journal* 810.
- Rietjens, J.A., van der Heide, A., Vrakking, A.M., Onwuteaka-Philipsen, B.D., van der Maas, P.J., and van der Wal, G., 'Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands' (2004) 141(3) *Ann Intern Med* 178.
- Rietjens, J.A., Voorhees, J.R., van der Heide, A., and Drickamer, M.A., 'Approaches to suffering at the end of life: the use of sedation in the USA and Netherlands' (2014) 40(4) *Journal of Medical Ethics* 235.
- Robb, N., 'Death in a Halifax hospital: a murder case highlights a profession's divisions' (1997) 157 *Canadian Medical Association Journal* 757.
- Robert, R., Salomon, L., Haddad, L., Graftieaux, J.P., Eon, B., and Dreyfuss, D., 'End of life in the intensive care unit: should French law be adapted?' (2014) 4(6) *Annals of Intensive Care* 6.
- Roberts, C.M., Seiger, A., Buckingham, R.J., and Stone, R.A., 'Clinician perceived good practice in end-of-life care for patients with COPD' (2008) 22 *Palliative Medicine* 855.
- Roquefeuil, B., Benezech, B., Batier, B., and Marchal, B., 'Analgesia by intraventricular injection of morphine' (1982) 23 *Aggressologie* 119.
- Rothman, D.J., *Strangers at the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making* (Aldine Transaction 1991).

- Rousseau, P.C., 'Existential suffering and palliative sedation: a brief commentary with a proposal for clinical guidelines' (2001) 18 *American Journal of Hospice Palliative Care* 151.
- Rousseau, P.C., 'Palliative sedation' (2002) 19 *American Journal of Hospice Palliative Care* 295.
- Rousseau, P., 'Palliative sedation in the management of refractory symptoms' (2004) 2(2) *Journal of Supportive Oncology* 181.
- Rousseau, P., 'The ethical validity and clinical experience of palliative sedation' (2000) 75(10) *Mayo Clin Proc* 1064.
- Rowe, D., Keating, A., and Walsh, E., 'Palliative Care Teamwork in the Republic of Ireland – The Key to Physical and Psychological Function' in Ling, J., and O'Siorain, L., (eds), *Palliative Care in Ireland* (Open University Press 2005).
- Royal College of General Practitioners, 'RCGP Commissioning Guidance in End of Life Care' (2013).
- Royal College of Physicians, 'National Care of the Dying Audit for Hospitals, England' (Royal College of Physicians 2014).
- Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2005).
- Royal Dutch Medical Association, 'Guideline for Palliative Sedation' (Royal Dutch Medical Association 2009).
- Royal Dutch Medical Association, 'The Role of the Physician in the Voluntary Termination of Life' (June 2001).
- Rys, S., Deschepper, R., Mortier, F., Deliens, L., Atkinson, D., Bilsen, J., 'The moral difference or equivalence between continuous sedation until death and physician-assisted death: word games or war games?' (2012) 9 *Bioethical Inquiry* 171.
- Rys, S., Mortier, F., Deliens, L., Deschepper, R., Battin, M., and Bilsen, J., 'Continuous sedation until death: moral justifications of physicians and nurses-a content analysis of opinion pieces' (2013) 16 *Medicine, Health Care and Philosophy* 533.
- Sachs, M.A., 'Sedation – Unconsciousness – Anaesthesia! What are we Talking About?' in Tännsjö, T., (ed.), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004).
- Salmanticenses, *Cursus Theologicus* (Brussels 1879).
- Salamagne, M.H., and Thominet, P., (eds) *Accompagner: Trente ans de soins palliatifs en France* (Editions Demopolis 2015).
- Sampson, E.L., Thuné-Boyle, I., Kukkastenvchmas, R., Jones, L., Tookman, A., King, M., and Blanchard, M.R., 'Palliative care in advanced dementia; A mixed methods approach for the development of a complex intervention' (2008) *BMC Palliative Care* 8.
- Sandman, L., 'What's the use of human dignity within palliative care?' (2002) 3(2) *Nursing Philosophy* 177.
- Saunders, C., 'Drug treatment of patients in the terminal stages of cancer' (1960) 1(1) *Current Medicine and Drugs* 16.
- Saunders, C., 'The care of the terminal stages of cancer' (1967) 41 *Annals of the Royal College of Surgeons* 162.
- Saunders, C., 'The evolution of palliative care' (2001) 94(9) *Journal of the Royal Society of Medicine* 430.
- Saunders, C., 'The symptomatic treatment of incurable malignant disease' (1964) 4 *Prescriber's Journal* 68.
- Saunders, C., *Watch With Me: Inspiration for a Life in Hospice Care* (Mortal Press 2003).
- Savill, R., 'Woman ends 'right to die' food protest' *The Daily Telegraph* (13 August 2005).

- Sayare, S., 'French Families Challenge Doctors on Wrenching End-of-Life Decisions' *New York Times* (31 July 2014).
- Schopenhauer, A., *The Basis of Morality* (A. Bullock tr, Dover Publications 2012).
- Schostak, Z., 'Jewish ethical guidelines for resuscitation and artificial nutrition and hydration of the dying elderly' (1994) 20 *Journal of Medical Ethics* 93.
- Schotsmans, P., 'Palliative Care: A Relational Approach' in ten Have, H., and Clark, D., (eds) *The Ethics of Palliative Care: European Perspectives* (Oxford University Press 2002).
- Schroeder, D., 'Dignity: two riddles and four concepts' (2008) 17(2) *Cambridge Quarterly of Healthcare Ethics* 230.
- Schur, S., Weixler, D., Gabl, C., Kreye, G., Likar, R., Masel, E.K., Mayrhofer, M., Reiner, F., Schmidmayr, B., Kircheiner, K., and Watzke, H.H., 'Sedation at the end of life – a nation-wide study in palliative care units in Austria' (2016) 15(50) *BMC Palliative Care*
- Select Committee, *'Dying with Dignity'* (Québec, March 2012).
- Selman, L., Harding, R., Beynon, T., Hodson, F., Hazeldine, C., Coady, E., Gibbs, L., and Higginson, I.J., 'Modelling services to meet the palliative care needs of chronic heart failure patients and their families: current practice in the UK' (2007) 21(5) *Palliative Medicine* 385.
- Selva, C., 'International control of opioids for medical use' (1997) 4(6) *European Journal of Palliative Care* 194.
- Sepúlveda, C., Marlin, A., Yoshida, T., and Ullrich, A., 'Palliative care: the World Health Organization's global perspective' (2002) 24(2) *Journal of Pain and Symptom Management* 91.
- Seale, C., 'End-of-life decisions in the UK involving medical practitioners' (2009) 23 *Palliative Medicine* 198
- Seale, C., and Addington-Hall, J., 'Euthanasia: why people want to die earlier' (1994) 39(5) *Social Science and Medicine* 647.
- Sepúlveda, C., Marlin, A., Yoshida, T., and Ullrich, A., 'Palliative care: the World Health Organization's global perspective' (2002) 24(2) *Journal of Pain and Symptom Management* 91.
- Seymour, J.E., JanssensR., and Broaeckaert, B., 'Relieving suffering at the end of life: practitioners' perspectives on palliative sedation from three European countries' (2007) 64 *Social Science & Medicine* 1679.
- Sheldon, T., "'Terminal sedation" different from euthanasia, Dutch ministers agree' (2003) 327(7413) *British Medical Journal* 465.
- Sicard, D., *Penser solidairement la fin de vie – Commission de réflexion sur la fin de vie en France'* (Décembre 2012).
- Simon, A., Kar, M., Hinz, J., and Beck, D., 'Attitudes towards terminal sedation: an empirical survey among experts in the field of medical ethics' (2007) 6 *BMC Palliative Care* 1472.
- Smith, S.W., *End-of-Life Decisions in Medical Care: Principles and Policies for Regulating the Dying Process* (Cambridge University Press 2012).
- Smith, W., and Lockwood, J., *Chambers Murray Latin-English Dictionary* (Chambers 1976).
- Société Française d'Accompagnement et de Soins Palliatifs, «Avis 029 du 10 mars 2016 du Comité Scientifique de la SFAP Concernant la loi n° 2016-2087 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie»
- Société Française d'Accompagnement et de Soins Palliatifs, 'Evaluation du caractère réfractaire de la souffrance' (SFAP, May 2017).

- Société Française d'Accompagnement et de Soins Palliatifs, *'Evaluation du Pronostic vital engagé à court terme'* (SFAP, May 2017).
- Somerville, M., *Death Talk* (2nd edn, McGill-Queen's University Press 2014).
- Somerville, M., 'Human Rights and Medicine: The Relief of Suffering' in Cotler, I., and Eliadis, F.P., (eds) *International Human Rights Law: Theory and Practice* (Canadian Human Rights Foundation 1992).
- Sulmasy, D.P., 'The Ethics of Medically Assisted Nutrition and Hydration at the End of Life' in Youngner, S.J., and Arnold, R.M., (eds) *The Oxford Handbook of Ethics at the End of Life* (Oxford University Press 2016).
- Sulmasy, D.P., and Pellegrino, E.D., 'The rule of double effect: clearing-up the double talk' (1999) 159(6) *Arch Intern Med* 545.
- Spranzi, M., 'The French euthanasia debate: exception and solidarity' (2013) 22 *Cambridge Quarterly of Healthcare Ethics* 254.
- Stevens, J., 'A pathway to euthanasia? Family revive father doctors ruled wasn't worth saving' *Daily Mail* (13 February 2013).
- Stiefel, F., 'Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association of Palliative Care' (2001) 9(7) *Supportive Care in Cancer* 477.
- Stjernsward, J., Bruera, E., Joranson, D., Allende, S., Montejo, G., Tristan, L.Q., Castillo, G., Schoeller, T., Antonieta, M., Pazos, R., Wenk, R., Pruvost, M., De Lima, L., Mendez, E., Núñez Olarte, J., Olalla, J.F., Vanegas, G., 'Opioid availability in Latin America: The Declaration of Florianopolis' (1995) 10(3) *Journal of Pain and Symptom Management* 233.
- Swart, S.J., Brinkkemper, T., Rietjens, J.A., Blanker, M.H., van Zuylen, L., Ribbe, M., Zuurmond, W.W., van der Heide, A., and Perez, R.S., 'Physicians' and nurses' experiences with continuous palliative sedation in the Netherlands' (2010) 170(14) *Arch Intern Med* 1271.
- Swart, S.J., Rietjens, J.A.C., Brinkkemper, T., van Zuylen, L., van Burg-Verhage, W.A., Zuurmond, W.W.A., Ribbe, M.W., Blanker, M.H., Perez, R., and van der Heide, A., 'Palliatieve sedatie na introductie KNMG-richtlijn' (2011) 155 *Ned Tijdschr Geneesk* A2857
- Swart, S.J., Rietjens, J.A.C., van Zuylen, L., Zuurmond, W.W.A., Perez, R.S.G.M., van der Maas, P.J., van Delden, J.J.M., and van der Heide, A., 'Continuous palliative sedation for cancer and noncancer patients' (2012) 43(2) *Journal of Pain and Symptom Management* 172.
- Sykes, N.P., 'Clinical Aspects of Palliative Sedation' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- Sykes, N., 'One chance to get it right: understanding the new guidance for care of the dying person' (2015) 115(1) *Br Med Bull* 143.
- Sykes, N., and Thorns, A., 'The use of opioids and sedatives at the end of life' (2003) 4 *The Lancet Oncology* 312.
- Tang, S.T., and Chen, C.H., 'Place of Death and Dying' in Cohen, J., and Deliens, L., *A Public Health Perspective on End of Life Care* (Oxford University Press 2012).
- Tännsjö, T., 'Terminal Sedation: A Substitute for Euthanasia' in Tännsjö, T., (ed.), *Terminal Sedation: Euthanasia in Disguise?* (Springer 2004).
- Task Force on Palliative Care, Last Acts Campaign, and Robert Wood Johnson Foundation, 'Precepts of palliative care' (1998) 1(2) *Journal of Palliative Medicine* 109.
- Taylor, B.R., and McCann, R.M., 'Controlled sedation for physical and existential suffering?' (2005) 8(1) *Journal of Palliative Medicine* 144.

- ten Have, H., and Welie, J.V.M., 'Palliative sedation versus euthanasia: an ethical assessment' (2014) 47(1) *Journal of Pain and Symptom Management* 123.
- The Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales, 'A policy framework for commissioning cancer services' (Department of Health 1995).
- The Medical Council, 'A Guide to Ethical Conduct and Behaviour and to Fitness to Practise' (Dublin 1981).
- 'The Palliative Care Trainers Declaration of Cape Town' (2003) 6(3) *Journal of Palliative Medicine* 339.
- The Poznan Declaration* (1998) 6(2) *European Journal of Palliative Care* 61.
- The Scottish Government, 'Strategic Framework for Action on Palliative and End of Life Care 2016–2021' (The Scottish Government 2015).
- Thorns, A., 'The Use of Sedation at the End of Life' in Worthington, R., (ed) *Ethics and Palliative Care: A Case Based Manual* (CRC Press 2002).
- Thouvenin, D., 'La loi n° 2005–370 du 22 avril 2005, dite loi Leonetti: la médicalisation de la fin de vie' in Ferry, J.M. and Martin, N., *Fin(s) de vie: Le débat* (Presse Universitaires de France 2012).
- Tiernan, E., O'Connor, M., O'Siorain, L., and Kearney, M., 'A prospective study of preferred versus actual place of death among patients referred to a palliative home care service' (2002) 95(8) *Irish Medical Journal* 232.
- Turner, J.S., Michell, W.L., Morgan, C.J., and Benatar, S.R., 'Limitation of life support: frequency and practice in a London and a Cape Town intensive care unit' (1996) 22 *Intensive Care Medicine* 1020.
- Twycross, R.G., 'Choice of strong analgesic in terminal cancer: diamorphine or morphine?' (1977) 3 *Pain* 93.
- Twycross, R.G., 'The Brompton Cocktail' in Bonica, J.J. and Ventafridda, V., (eds), *International Symposium on Pain of Advanced Cancer* (Vol. 2, Raven Press 1979).
- Twycross, R., 'Where There is Hope, There is Life: A View from the Hospice' in Keown, J. (ed.), *Euthanasia Examined* (Cambridge University Press 1995)
- United Nations, Department of Economic and Social Affairs, Population Division, 'World Population Ageing Report 2015' (ST/ESA/SER.A/390).
- van Beek, K., Woitha, K., Ahmed, N., Menten, J., Jaspers, B., Engels, Y., Ahmedzai, S.H., Vissers, K., and Hasselaar, J., 'Comparison of legislation, regulations and national health strategies for palliative care in seven European countries (Results from the Europall Research Group): a descriptive study' (2013) 13 *BMC Health Services Research* 275.
- van Delden, J.J., 'Terminal sedation: source of a restless ethical debate' (2007) 33(4) *Journal of Medical Ethics* 187.
- van Delden, J.J.M., 'The Ethical Evaluation of Continuous Sedation at the End of Life' in Sterckx, S., Raus, K., and Mortier, F., (eds), *Continuous Sedation at the End of Life: Ethical, Clinical and Legal Perspectives* (Cambridge University Press 2013).
- van den Block, L., 'Palliative Care in Primary Care' in Cohen, J., and Deliens, L., *A Public Health Perspective on End of Life Care* (Oxford University Press 2012).
- van den Block, L., Pivodic, L., Pardon, K., Donker, G., Miccinesi, G., Moreels, S., Alonso, T.V., Deliens, L., and Onwuteaka-Philipsen, B., 'Transitions between health care settings in the final three months of life in four EU countries' (2015) 25(4) *European Journal of Public Health* 569.
- van der Heide, A., van Delden, J.J.M., and Onwuteaka-Philipsen, B.D., 'End-of-life decisions in the Netherlands over 25 years' (2017) 377 *N Engl J Med* 492.

- van der Steen, J., Helton, M.R., Sloane, P.D., and Ribbe, M.W., 'Palliative Care in Institutional Long-Term Care Settings' in Cohen, J., and Deliens, L., (eds) *A Public Health Perspective on End of Life Care* (Oxford University Press 2012).
- van der Velden, L.F.J., Francke, A.L., Hingstman, L., and Willems, D.L., 'Dying from cancer or other chronic diseases in the Netherlands: ten-year trends derived from death certificate data' (2009) 8 *BMC Palliative Care* 4.
- van der Wal, G., van der Heide, A., Onwuteaka-Philipsen, B.D., and van der Maas, P.J., *'Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie'* (Utrecht, 2003).
- van Dijk, P., and van Hoof, G.J.H., *Theory and Practice of the European Convention on Human Rights* (3rd edn, Martinus Nijhoff 1998).
- Ventafriidda, V., Ripamonti, C., De Conno, F., Tamburini, M., and Cassileth, B.R., 'Symptom prevalence and control during cancer patients' last days of life' (1990) 6 *Journal of Palliative Care* 7.
- Verhagen, E.H., de Graeff, A., Verhagen, C., and van Wijlick, E.H.J., *'Palliative Sedation'* (Integraal Kankercentrum Nederland 2009).
- Verkerk, M., van Wijlick, E., Legemaate, J., and de Graeff, A., 'A national guideline for palliative sedation in The Netherlands' (2007) 34(6) *Journal of Pain and Symptom Management* 666.
- WaldingM., and Andrews, C., 'Preventing and managing pressure sores in palliative care' (1995) 11(1) *Professional Nurse* 33.
- Waldron, J., *The Harm in Hate Speech* (Harvard University Press 2012).
- Walling, A.M., Asch, S.M., Lorenz, K.A., Roth, C.P., Barry, T., Kahn, K.L., and Wenger, N.S., 'The quality of care provided to hospitalized patients at the end of life' (2010) 170(12) *Arch Intern Med* 1057.
- Weller, P., *New Law and Ethics in Mental Health Advance Directives: The Convention on the Rights of Persons with Disabilities and the Right to Choose* (Routledge 2013).
- West, E., Roeline Pasma, H., Galesloot, C., Lokker, M.E., and Onwuteaka-Philipsen, B., 'Hospice care in the Netherlands: who applies and who is admitted to inpatient care?' (2016) 16 *BMC Health Services Research* 33.
- Wetzel, R.C., and Nicholson, C.E., 'Research in Pediatric Critical Care' in FuhrmanB.P., and Zimmerman, J., (eds), *Pediatric Critical Care* (4th edn, Elsevier 2011).
- Williams, G., 'Acts and omissions in treatment withdrawal: conceptual problems and policy decisions' (2008) 39 *Cambrian Law Review* 75.
- Williams, G., *Intention and Causation in Medical Non-killing: The Impact of Criminal Law Concepts on Euthanasia and Asisted Suicide* (Routledge-Cavendish 2007).
- Williams, G., 'The principle of double effect and terminal sedation' (2001) 9 *Medical Law Review* 41.
- Wilson, F., Ingleton, C., Gott, M., and Gardiner, C., 'Autonomy and choice in palliative care: time for a new model?' (2014) 70(5) *Journal of Advanced Nursing* 1020.
- Wood, J., and Gartrell, T., *'Equity of geographical access to inpatient hospice care within North West England: A Geographical Information Systems (GIS) approach'* (North West Public Health Observatory 2002).
- Woods, S., *Death's Dominion: Ethics at the End of Life* (Open University Press 2007).
- World Health Organization, *'Cancer Pain Relief'* (World Health Organization 1986).
- World Health Organisation, *Cancer Pain Relief: With a Guide to Opioid Availability* (2nd edn, World Health Organization1996).
- World Health Organization, *'Constitution of the World Health Organization'* (1946).

- World Health Organization, *'Strengthening of palliative care as a component of integrated treatment within the continuum of care'* (EB134.R7).
- World Health Organization, *'The Solid Facts: Palliative Care'* (World Health Organization 2004).
- World Health Organization, *'WHO Model List of Essential Medicines'* (20th list, March 2017).
- World Medical Association, *'Declaration of Venice on terminal illness'* (1983) 287(6405) *British Medical Journal* (Clinical Research Ed.) 1646.
- World Medical Association, *'WMA Declaration on End-of-Life Medical Care'* (Uruguay 2011).
- Writing Group for the Consortium for Health and Human Rights, *'A call to action on the 50th anniversary of the Universal Declaration of Human Rights. Health and human rights'* (1998) 3(2) *Health and Human Rights* 7.
- Wuhan Declaration* (2009).
- Yaksh, T.L., and Rudy, T.A., *'Analgesia mediated by a direct spinal action of narcotics'* (1976) 192(4246) *Science* 1357.
- Young, E., *'Ethical issues at the end of life'* (1998) 9 *Stanford Law and Policy Review* 267.
- Youngner, S.J., and Kimsma, G.K., *Physician-Assisted Death in Perspective: Assessing the Dutch Experience* (Cambridge University Press 2012).

Online resources

- Association for Palliative Medicine, *'Welcome'* <<http://apmonline.org/>> accessed 7 February 2017.
- Cancer Clinical Practice Guidelines*, *'Oncoline'* <<http://www.oncoline.nl/pain>> accessed 22 August 2017.
- Cancer Clinical Practice Guidelines*, *'What to find on Oncoline'* <<http://www.oncoline.nl/index.php?language=en>> accessed 22 August 2017.
- Cancer ResearchUK, *'Cancer Incidence Statistics'* <<http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence#heading-Zero>> accessed 20 February 2017.
- Clark, C., *'Palliative medicine as a specialty'* (30 June 2014) <<http://endoflifestudies.academicblogs.co.uk/palliative-medicine-as-a-specialty/>> accessed 20 March 2017.
- European Association of Palliative Care, *'About the EAPC'* <<http://www.eapcnet.eu/Corporate/AbouttheEAPC.aspx>> accessed 19 March 2017.
- European Association of Palliative Care, *'Definition of palliative care'* <<http://www.eapcnet.eu/Corporate/AbouttheEAPC/DefinitionandAims.aspx>> accessed 3 March 2017.
- European Association of Palliative Care, *'EAPC Membership and Benefits'* <<http://www.eapcnet.eu/Themes/Membership.aspx>> accessed 15 November 2017.
- European Pathway Association, *'Care Pathways'* <<http://e-p-a.org/care-pathways/>> accessed 3 November 2017.
- France 24, *'France opens the door to medically-assisted suicide'* France 24 (Paris, 26 June 2014) <<http://www.france24.com/en/20121219-france-medically-assisted-suicide-euthanasia-healthcare-reform-hollande>> accessed 4 September 2017.
- Good, P., Richard, R., Syrmis, W., Jenkins-Marsh, S., Stephens, J., *'Medically assisted hydration to assist palliative care patients'* <http://www.cochrane.org/CD006273/SYMPT_medicallly-assisted-hydration-to-assist-palliative-care-patients> accessed 21 May 2017.
- Hospice UK, *'Facts and Figures'* <<https://www.hospiceuk.org/media-centre/facts-and-figures>> accessed 21 March 2017.
- International Association for the Study of Pain, *'IASP Taxonomy'* <<http://www.iasp-pain.org/Education/Content.aspx?ItemNumber=1698&navItemNumber=576#Pain>> accessed 22 August 2017.

- Irish Association of Palliative Care, 'About Us' <<http://www.iapc.ie/about-us/>> accessed 16 November 2017.
- Irish Association of Palliative Care, 'What does the Irish Association of Palliative Care do?' <<http://www.iapc.ie/what-we-do.php>> accessed 7 February 2017.
- Irish Cancer Society, 'Home Night Nursing' <<http://www.cancer.ie/how-we-can-help/nursing/home-night-nursing>> accessed 8 May 2017.
- Irish Hospice Foundation, 'About Us' <<http://hospicefoundation.ie/about-us/>> accessed 7 February 2017.
- Irish Hospice Foundation, 'Hospice Friendly Hospitals Programme' <<http://hospicefoundation.ie/what-we-do/hospice-friendly-hospitals/>> accessed 7 February 2017.
- Love, B., and Pineau, E., 'France's Hollande targets rich in tax-rise manifesto' *Reuters* (26 January 2012) <<http://www.reuters.com/article/france-hollande-idINDEE80P0BI20120126>> accessed 4 September 2017.
- McGill, 'Palliative Care McGill: Balfour Mount' <<https://www.mcgill.ca/palliativecare/portraits-0/balfour-mount>> accessed 19 March 2017.
- Our Lady's Hospice & Care Services, 'Our Heritage' <<http://www.olh.ie/6-about-us/38-our-heritage/>> accessed 7 February 2017.
- Société Française d'Accompagnement et de Soins Palliatifs, 'Enquête Loi Clayes/Leonetti' <<http://www.sfap.org/actualite/enquete-loi-clayesleonetti>> accessed 4 September 2017.
- Société Française d'Accompagnement et de Soins Palliatifs, 'Histoire de la SFAP' <<http://www.sfap.org/rubrique/histoire-de-la-sfap>> (accessed 3 September 2017).
- Société Française d'Accompagnement et de Soins Palliatifs, 'Résultats Enquête loi Clayes-Leonetti' <<http://www.sfap.org/system/files/analyse-resultats-enque-loi-claays-leonetti-vc-graph.pdf>> accessed 4 September 2017.
- St Christopher's Hospice, 'History' <<http://www.stchristophers.org.uk/about/history>> accessed 7 February 2017.
- St Joseph's Hospice, 'Our history' <<https://www.stjh.org.uk/about-us/our-history>> accessed 7 February 2017.
- The Prague Charter: Urging governments to relieve suffering and recognize palliative care as a human right*, <<https://hospicecare.com/uploads/2013/6/PragueCharterPetition.pdf>> accessed 30 October 2017.
- 'The Royal Dutch Medical Association' <<http://knmg.artsennet.nl/Over-KNMG/About-KNMG.htm>> accessed 20 August 2017.
- Willsher, K., 'Suicide of elderly French couple stirs euthanasia debate' *The Guardian* (London, 25 November 2013) <<https://www.theguardian.com/world/2013/nov/25/suicide-elderly-couple-france-paris-euthanasia-debate>> (accessed 4 September 2017).
- World Health Organization, 'Essential Medicines' <http://www.who.int/topics/essential_medicines/en/> accessed 30 October 2017.
- World Health Organization, 'WHO Definition of Palliative Care' <<http://www.who.int/cancer/palliative/definition/en/>> accessed 4 March 2017.

Table of cases

- A, B, and C v Ireland* [2010] ECHR 2032
- Airedale N.H.S. v Bland* [1993] AC 789
- An NHS v D* [2012] EWHC 885 (COP)
- An NHS Trust v H* [2001] 2 FLR 501
- An NHS Trust v M* [2001] 2 FLR 367
- Barnett v Chelsea and Kensington Hospital Management Committee* [1969] 1 QB 428

250 Bibliography

- BB v France*, App no 30930/96 (ECtHR, 7 September 1998)
- Bensaid v United Kingdom* (2001) ECHR 82
- Bouyid v Belgium*, App no 23380/09 (28 September 2015)
- Burke, R (on the application of) v The General Medical Council* [2004] EWHC 1879 (Admin)
- Carter v Canada (Attorney General)* 2012 BCSC 886
- Compassion in Dying v Washington* 79 F. 3d 790, 1996 US App Lexis 3944
- Cruzan v Director Missouri Department of Health* 497 US 261 (1990)
- D v United Kingdom* (1997) 24 EHRR 423
- Fitzpatrick and Another v K and Another* [2008] IEHC 104
- Fleming v Ireland & Ors* [2013] IEHC 2, [2013] IESC 19
- Frenchay Healthcare NHS Trust v S* [1994] 2 All ER 403
- Garnier, Conseil d'État*, 29 July 1994
- Governor of X Prison v McD* [2015] IEHC 259
- Glass v United Kingdom* (2004) 39 EHRR 15
- HE v A Hospital Trust* [2003] EWHC 1017
- Heeney v Dublin Corporation* [1998] IESC 23
- Herczegfalvy v Austria* (1992) 15 EHRR 437
- Hoge Raad (Supreme Court of the Netherlands)*, 24 December 2002, NJ 2003, 167
- Hoge Raad (Supreme Court of the Netherlands)*, 21 June 1994, NJ 1994, 656
- Hoge Raad (Supreme Court of the Netherlands)*, 27 November 1984, NJ 1985, No. 106
- Il v Bulgaria App* 44082/98, (9 June 2005)
- In the Matter of Art 26 of the Constitution and the Health (Amendment) (No 2) Bill 2004* [2005] IESC 7
- Ireland v United Kingdom* [1978] ECHR 1
- Keenan v United Kingdom* (2001) 33 EHRR 913
- Kudla v Poland* (2000) 35 EHRR 198
- L v Lithuania* (2008) 46 EHRR 22
- Lambert and Others v France App* 46043/14, (ECtHR, 25 June 2015)
- Mayzit v Russia (App. 63378/00)*, (20 January 2005)
- Mouisel v France, App No* 67263/01 (14 November 2002), (2004) 38 EHRR 34
- Nederlandse Jurisprudentie* 1973, no. 183, *District Court of Leeuwarden*, 21, February 21, 1973
- Nevmerzhitsky v Ukraine* (2006) 43 EHRR 32
- Pretty v United Kingdom* (2002) 35 EHRR 1
- Price v the United Kingdom, App no* 33394/96, (ECtHR, 10 July 2001)
- Primary Care Trust* [2011] EWHC 2443 (Fam)
- The People (DPP) v Douglas and Hayes* [1985] ILRM 25
- The People (DPP) v Murray* [1977] IR 360
- R v Adams* [1957] Crim LR 773
- R v Central Birmingham Health Authority, ex parte Walker* (1987) 3 BMLR 32
- R v Cox* (1992) 12 BMLR 38
- R v Gibbins and Proctor* (1918) 13 Cr App Rep 134
- R v Secretary of State for Social Services ex parte Hincks* (1979) 123 Sol Jo 436
- R v Stone and Dobinson* [1977] QB 354
- R v Woolin* [1998] 4 All ER 103
- Raninen v Finland, App no* 2097 2/92 (16 December 1997)
- R(Burke) v General Medical Council* [2006] QB 273, [2005] EWCA Civ 1003
- R(Nicklinson) v Ministry of Justice* [2013] EWCA Civ 961, [2013] HRLR 36
- R(Rose) v Thanet Clinical Commissioning Group* [2014] EWHC 1182 (Admin)

- Re C (Adult: refusal of treatment)* [1994] 1 *All ER* 819
- Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2011] EWHC 2443 (Fam), [2012] 1 *WLR* 1653
- Re T (Adult: Refusal of Medical Treatment)* [1992] 3 *WLR* 782, [1992] EWCA Civ 18
- Report of November 5, 1969, Yearbook of the European Convention on Human Rights*, Vol. XII (1969)
- Rodriguez v British Columbia* [1993] 3 *SCR* 519
- Ryan v Attorney General* [1965] *IR* 294
- Selmouni v France* (2000) 29 *EHRR* 403
- Senanyake, Cour administrative d'appel de Paris*, 9 June 1998
- State (C) v Frawley* [1976] 1 *IR* 365
- Swindon and Marlborough NHS Trust v S* [1995] 3 *Medical Law Review* 84
- Tanko v Finland*, App no 23634/94 (Commission Decision, 19 May 1994)
- Tatete v Switzerland*, App no 41874/98 (ECtHR, 6 July 2000)
- Tysiak v Poland* (2007) 45 *EHRR* 42
- Vacco v Quill* 521 *US* 793 (1997)
- Valašinas v Lithuania*, App no 44558/98, (24 July 2001)
- W Healthcare NHS Trust v KH* [2004] EWCA Civ 1324, [2005] 1 *WLR* 834
- Ward of Court (withholding medical treatment) (No 2)*, *Re*, [1996] 2 *IR* 79, [1995] 2 *ILRM* 401
- W (by her litigation friend B) v M (by her litigation friend, the Official Solicitor) and S and A NHS NHS Primary Care Trust* [2011] EWHC 2443 (Fam)
- X v Denmark* (1992) 15 *EHRR* 437
- Z and Others v the United Kingdom* (2002) 34 *EHRR* 3

Table of legislation

Belgium

The Belgian Act on Euthanasia of May, 282002

England and Wales

Abortion Act 1967

Access to Palliative Care Bill 2015

Access to Palliative Care Bill 2017

Assisted Dying for the Terminally Ill Bill 2005

Medical Act 1983

Mental Capacity Act 2005

Palliative Care Bill 2006

Palliative Care Bill 2008

Council of Europe

European Convention for the Protection of Human Rights and Fundamental Freedoms 1950 (*European Convention on Human Rights, as amended*) (ECHR)

European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment, Strasbourg, 26.XI.1987 Text amended according to the provisions of Protocols No. 1 (ETS No. 151) and No. 2 (ETS No. 152), which entered into force on 1 March 2002

252 *Bibliography*

Recommendation Rec (2003) 24 of the Committee of Ministers to member states on the organisation of palliative care, adopted by the Committee of Ministers on 12 November 2003.

European Union

Charter of Fundamental Rights of the European Union [2010] OJ C83/380

France

Loi n° 91-748 du 31 juillet 1991 portant réforme hospitalière

Loi n° 99-477 du 9 juin 1999 visant à garantir le droit à l'accès aux soins palliatifs

Loi n° 2002-303 du 4 mars 2002 relative aux droits des malades et à la qualité du système de santé

Loi n° 2005-370 du 22 avril 2005 relative aux droits des malades et à la fin de vie

Loi n° 2016-87 du 2 février 2016 créant de nouveaux droits en faveur des malades et des personnes en fin de vie

Texte n° 301 (1977–1978) relative au droit de vivre sa mort présentée par M. Henri Caillavet

Ireland

Assisted Decision-Making (Capacity) Act 2015

Criminal Justice Act 1967

Criminal Justice Act 1964

Criminal Law (Suicide) Act 1993

Equal Status Act 2000

European Convention on Human Rights Act 2003

Health Act 2007 (Care and Welfare of Residents in Designated Centres for Older People) Regulations 2009

Irish Medicines Board (Miscellaneous Provisions) Act 2006

Medical Practitioners Act 1978

Medical Practitioners Act 2007

Medicinal Products (Prescription and Control of Supply) (Amendment) Regulations 2007, S.I. 201 of 2007

Misuse of Drugs (Amendment) Regulations 2007, S.I. 200 of 2007

Nurses Act 1950

Nurses Act 1985

Nurses and Midwives Act 2011.

Protection of Life During Pregnancy Act 2013

Luxembourg

Loi du 16 mars 2009 sur l'euthanasie et l'assistance au suicide

Netherlands

Dutch Penal Code

Medical Treatment Contracts Act 1994

Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001

New York

Palliative Care Information Act 2011

Palliative Care Access Act 2011

United Nations

Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment 1984

Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine, Oviedo 4.IV.1997

Convention on the Rights of Persons with Disabilities and Optional Protocol 2006

Convention on Psychotropic Substances 1971

International Covenant on Civil and Political Rights 1966

International Covenant on Economic, Social and Cultural Rights 1966

Single Convention on Narcotic Drugs 1961

Universal Declaration of Human Rights 1949

Index

- AAQ (availability, accessibility, acceptability and quality) framework 113–14
- abortion 10, 107–9
- acts and omissions 3, 54, 74–6, 78
- advance healthcare directives 74, 93, 96–8, 143; basic care 97–8; France 193, 194, 195, 197, 199, 200, 201, 206, 211
- Africa: African Palliative Care Association 22, 110; hospitals 28; Sub-Saharan 117
- AIDS 23, 102–3
- American Medical Association 168
- amyotrophic lateral sclerosis/motor neurone disease 23, 164
- Antonius-IJsselmonde nursing home 155
- Aquinas, Thomas 58
- Argentina 19
- Armenia 117
- artificial nutrition and hydration (ANH) 3, 6, 11, 44–6, 80, 104, 125; act or omission 74–6, 78; advance healthcare directive 74, 93, 97–8; bowel obstruction 73; delirium, terminal 73; demand for 91–3; dementia, tube feeding of patients with 72–3; distinction between withholding and withdrawing 78–9; EAPC recommended framework 151; France: Claeys-Leonetti law 208–9, 210, 212; General Medical Council guidance 127–8; Irish Association of Palliative Care 21, 147, 148–9; Irish Medical Council guidance 141; KNMG (Royal Dutch Medical Association) Guideline for Palliative Sedation 163, 165, 171–2, 178, 179; lack capacity: best interests assessment 71, 74–9; lack of definitive position on 45–6, 72, 149, 209; lack of hydration and hastening of death 72, 163, 165; Liverpool Care Pathway 129; medical treatment or care 76–8, 172, 201, 208, 212; NICE guidance 132, 133; Nursing and Midwifery Board of Ireland 144; palliative sedation without 70–9, 80, 158–9, 163, 165, 171–2, 178, 179, 216–17; patient autonomy in withholding and withdrawal of 73–4; refusal of treatment 71, 73–4, 97–8, 193, 199; tube feeding and mortality 73
- Asia Pacific Hospice Palliative Care Network 21
- assisted suicide 82, 91, 128, 138, 200, 202; physician-assisted suicide *see separate entry*
- Association for Palliative Medicine of Great Britain and Ireland 20, 22, 123, 149
- Association pour le Droit de Mourir dans la Dignité (Association for the Right to Die in Dignity) 184, 201
- Australia 22, 27
- Austria 34
- autonomy 32, 46, 81, 127, 135, 143, 189, 196, 217–18; capacity in Ireland and England and Wales 94–8; communitarian model of 87; conflict of medical paternalism and 184, 186, 187–8, 202, 213; decision ecology model 87; defining concept of 82–98; demand for medical treatment 82, 91–3, 97; dignity and 99; euthanasia and 53, 84, 211; explain and discuss palliative sedation 170, 181, 218; France: Claeys-Leonetti law 202, 203, 206, 209, 213; France: Leonetti's law 193–5, 197, 198, 199; informed consent 88–9; law and patient 87–9; liberal conception of 84–7, 180, 182; place of death 29, 30; reduction in consciousness with sedation 62, 89; refusal of medical treatment 86,

- 89–91; relational 87; reversible causes of confusion 95; right of 10, 44, 74, 81, 83, 88, 90–1, 117–18, 119, 124, 169, 170, 189, 203, 213, 217; role in advancing palliative care goals 83–4; social embeddedness 85–6, 87; withholding and withdrawal of ANH and patient 73–4
- Azerbaijan 117
- barbiturates 40
- battery 88
- bed sores, prevention of 32
- Belarus 117
- Belgium: autonomy 84; consent for sedation 89; hospitals 27; integral end-of-life care 7; physician-assisted suicide 8; sedation 34, 63, 71, 89; sedation without ANH 71
- belief and conscience, freedom of 100
- benzodiazepines 40, 42, 177–8; midazolam 40, 62, 178, 209
- best interests: assessment if lack capacity 71, 74–9, 95–6, 216–17; doctor's obligation to act in patient's 93, 97; IAPC position paper on artificial hydration 148–9; private and family life 107; therapeutic necessity and 104
- blood transfusion 90
- bodily integrity 96; ANH by way of nasogastric tube 77; right to 11, 81, 82, 106–9
- bowel obstruction and ANH 73
- Brompton Cocktail 18
- Cajetan, Cardinal 58
- Calman–Hine Report (1995) 121
- Canada 19, 22; double effect in courts 66–7; hospitals 27
- cancer 43, 108, 139, 158; Calman–Hine Report (1995) 121; development of hospice and palliative care 16, 17–19; dying at home 29, 158; home care services 31; increase in incidence of 2, 9; Integraal Kankercentrum Nederland 160, 167–8, 175; NICE 132; opioids 41; right to palliative care 111
- capacity 81–2, 88; advance healthcare directive 74, 93, 96–7; best interests assessment if lack 71, 74–9, 95–6, 216–17; euthanasia 8–9; in France 192–3, 196; functional test for 94, 95; in Ireland and England and Wales 94–8; presumption that adult patients have 73, 94, 126; refusal of all forms of nutrition 93; refusal of treatment 90–1; respect for private and family life of patient lacking 106–7
- Cape Town Declaration 22, 110
- care homes 157, 158
- care pathway: definition 128; demise of Liverpool Care Pathway (LCP) 128–30
- caregiver's leave 189, 220
- categories of palliative care patients, expansion in 23–5; community setting 29
- charities 16, 19, 20, 26, 31, 120, 130, 185
- chronic obstructive pulmonary disease (COPD) 2, 23, 24, 29, 164, 168
- Cochrane Reviews (2008 and 2014) 45–6, 72, 149
- commencement of dying process: lack of bright-line test 24
- communication 99, 123, 127, 130, 132, 133, 143, 180; honest 88; KNMG (Royal Dutch Medical Association) Guideline 169–71, 181
- communitarian model of autonomy 87
- community setting 28–32
- conscience and belief, freedom of 100
- consciousness, reduction in 148, 161, 167; double effect 61–2, 65, 66, 68–9, 216
- consent 86; degrading treatment: lack of 103; double effect 69, 181; France: informed 187, 190, 209, 210; Ireland: dignity and informed 143; KNMG (Royal Dutch Medical Association) Guideline for Palliative Sedation 169–71, 181; medical treatment: informed 88–9
- consequentialism 59
- constipation 32
- continuous deep sedation 34, 71, 175, 176–7; EAPC recommended framework 150–1; France 91, 201, 202–7, 208, 209, 210, 211, 212–14
- contract, breach of 219
- Council of Europe 48
- criminal law 102, 106, 181, 191, 216; battery 88; murder 54–7, 67–8, 74–6, 92
- Czech Republic 22
- De Simone, Gustavo 19
- De Wijkerslooth, Joan 158–9, 181
- decision ecology model of autonomy 87
- definitions 4; care pathway 128; degrading treatment 102; end-of-life care 7;

- cuthanasia 7–9; inhuman treatment 102;
- palliative care 4–6, 83, 99, 188–9;
- sedation 34–8, 44; specialist palliative care 6–7
- degrading treatment *see* inhuman and degrading treatment, protection from
- delirium 39, 42, 178; ANH and terminal 73
- dementia 23, 72–3
- Denmark 22; sedation 34; sedation without ANH 71
- deontology 59
- development and practice of palliative care 15–47; development of hospices 16–19, 183; emergence of modern palliative care 19–23; expansion in categories of palliative care patients 23–5; palliative care practices 32–46; palliative care providers 25–32
- diamorphine 68, 106
- dignity 11, 32, 81–2, 93, 96, 98–109, 113, 116, 122, 184, 218; autonomy and 99; decision-making framework 109; France: Kouchner's law 190; France: Leonetti's law 193–4, 198; inadequate care as inhuman or degrading treatment 101–6, 218; informed consent 143, 187; NICE guidance 132; Nursing and Midwifery Board of Ireland 142–3; objective sense 99–100; private and family life: right to physical integrity 106–9; subjective sense 99, 100; timely decision-making 108
- double effect 3, 36, 54, 57–70, 80, 88, 142, 148, 181, 216–17; act must be morally good or neutral 59, 60–1; bad effect foreseen and tolerated, good effect is directly intended 59, 62–5; bad effect should not be means through which good effect achieved 59, 61–2; consent 69; in courts 66–8, 69–70, 80; criteria for 59–66; development of reasoning 58–9; France 195, 200, 209, 210, 213; process rather than on-off decision 64; reasons for carrying out good act must exceed unintended bad effect 59, 65–6; reduction in consciousness 61–2, 65, 66, 68–9, 216; significance of 68–70
- Doyle, Derek 20
- drug trafficking 115
- drugs used for sedation 40–4, 132; benzodiazepines *see separate entry*; KNMG (Royal Dutch Medical Association) Guideline 173, 177–8; method of administering 41; opioids *see separate entry*
- duty of care 75, 92, 136
- Dworkin, R. 85
- eastern Europe 28
- elder abuse 219
- elimination problems 32
- empathy 99
- equality 81, 113, 117, 118, 126
- ethics 2, 92, 127, 157, 162; artificial nutrition and hydration 70, 79, 149; choice of terminology and 36, 37; committee 149; double effect 65, 66, 69, 70, 80, 148, 217; France 186, 190, 206–7, 208, 212, 214; legislation 214; *see also* autonomy
- European Association of Palliative Care (EAPC) 21, 25, 28, 84, 149–52, 168; dignity 98; palliative care leave 189
- European Union 2
- euthanasia 3, 4, 9, 93, 120, 152; autonomy 53, 84, 211; Belgium 7; categories 8; definition of 7–9; existential distress and palliative sedation 39, 52–3, 54, 163; fear of pain and 176; France 182–4, 188, 191, 192, 195, 198, 200, 201, 202, 206, 210–12, 220, 221; intention, palliative care and 37; legitimate distinction: specialist palliative care and 48–80, 215–17; murder: requisite intention 54–7; Netherlands: law and practice 49–54, 156, 157, 158–9, 163, 176, 220; palliative sedation and 11, 37, 39, 43–4, 48, 54, 57–70, 128, 158–9, 163, 165, 169, 172, 176–7, 179, 180, 195, 202, 206, 210–12, 213, 214, 215–17, 219, 220
- existential distress 52–3, 54, 84, 188–9; KNMG (Royal Dutch Medical Association) guidance 162–3; palliative sedation 39–40, 147, 151, 162–3, 204; Société Française d'Accompagnement et des soins Palliatifs (SFAP) guidance 204
- family of patient 62, 86, 88, 124, 125, 130, 141, 149, 151; best interests assessment 96; caregiver's leave 189, 220; France 184, 187–8, 189, 192–3, 195, 196, 197, 207; KNMG (Royal Dutch Medical Association) Guideline 164, 166, 170, 181
- fentanyl 40
- Finland 22

- Flanders: informed consent 89; sedation 34; sedation without ANH 71–2
- Ford, Gillian 22
- France 3, 11, 22, 219; autonomy 82, 182, 184, 186, 187–8, 189, 193–5, 196, 197, 198, 199, 202, 203, 206, 209, 213; continuous deep sedation 91, 201, 202–7, 208, 209, 210, 211, 212–14; hospices 16, 183; legal framework for palliative care in *see separate entry*
- futility, medical 192, 196, 209
- Garnier, Jeanne 16, 183
- General Medical Council 126–8
- general palliative care 6
- general practitioners 26, 28, 30, 31, 158, 167, 174, 175
- genetic materials 10
- Georgia 22
- Germany 22, 27
- Gury, J.P. 59
- health, right to 81, 105, 110, 111, 112–14, 115–16, 117, 219; AAAQ framework 113–14
- heart failure 24
- Hillier, Richard 20
- Hollande, François 198–9, 201
- home: care services 21, 30–1, 157; dying at 9, 29, 31, 86, 158, 175, 178, 184; hospitalisation teams 185; nursing teams 26; palliative care team 28
- Hospice UK 149
- hospices 25–6, 29, 88; development of 16–19, 183; emergence of modern palliative care 20; home care services 21, 30–1; Ireland 9, 16–17, 21, 26; Netherlands 156–7, 158, 175; role of 26; United Kingdom 17–19, 26, 30–1, 121, 131
- hospitals 17, 29; community 28; death in 9, 27, 29, 158; France 185, 186, 189, 207; Ireland 9, 27, 28; Netherlands 27, 157, 158, 175; palliative care 26–8; United Kingdom 20, 27, 131
- human dignity *see* dignity
- human rights 2, 4, 9, 10–11, 44, 81–118, 122, 126, 144, 145–6, 168, 180, 217–19; autonomy *see separate entry*; bodily/physical integrity, right to 11, 81, 82, 106–9; Cape Town Declaration 22, 110; dignity *see separate entry*; home care: availability of medications and medical equipment 178; inhuman and degrading treatment, protection from *see separate entry*; palliative care, right to 82, 109–17, 218–19
- Humbert, Vincent 191
- Hungary 22
- hydromorphone 40
- individualism 87
- inequalities 200
- information: patient 86, 88, 141, 143, 170, 176, 190, 211; transfer between healthcare staff 166, 177, 179
- inhuman and degrading treatment, protection from 11, 81, 82, 100, 116–17, 218; definitions 102; inadequate palliative care provision 101–6, 111; medical treatment absent consent 103; negative obligation 101; positive obligation 101–2, 109; severity threshold 104–5; therapeutic necessity 104
- intention(s) 37, 38, 49, 198, 216; double effect 57, 62–5, 66–7, 68, 69–70; double effect in courts 66–7, 68; House of Lords Select Committee on Medical Ethics: double effect 64–5; list of steps to clarify 70; multidisciplinary team 64; murder: identifying requisite 54–7; potential spectrum of 63–4
- international law: basis of right to palliative care in 112–15; progressive realisation 112, 117
- intrathecal pump 41
- Ireland 3, 9, 15–16, 25, 46, 49, 105, 117, 119–20; abortion 108–9; advance healthcare directives 97–8, 143; ANH, withdrawal of 75, 76, 77, 144; autonomy 73, 82, 87, 88, 90–1, 143; capacity 94–5, 96, 97–8; community setting 31; Constitution 87, 88, 90, 101, 106, 108, 109, 115–16, 143; EAPC recommendations 149; emergence of modern palliative care 19–21, 22; euthanasia 21; health, right to 115–16; Hospice Friendly Hospitals 28, 32; hospices 9, 16–17, 21, 26; hospitals 9, 27, 28; informed consent 89; inhuman or degrading treatment 101; Joint Committee on Health and Children 139–40; legal framework for palliative care in *see separate entry*; murder: identifying requisite intention 55–7; National Advisory Committee on Palliative Care 139; palliative care, right

- to 116–17; physical integrity, right to 106; refusal of treatment 90–1, 97–8; specialist palliative care 24, 146, 148
- Irish Association of Palliative Care (IAPC) 21, 139, 146–9
- Irish Cancer Society 31
- Irish Hospice Foundation (IHF) 20–1, 26, 28, 139
- Irish Medical Council (IMC) 22, 139, 140–2, 145, 146
- Irish Sisters of Charity 16–17
- Israel 22, 27
- Italy 22, 126; sedation 34; sedation without ANH 71
- Japan 27
- Jewish faith 79
- Jousset, Aurélie 183
- justification of specialist palliative care practices, legal and ethical 57–79; double effect *see separate entry*; palliative care without ANH 70–9
- Kazakhstan 117
- kidney disease, chronic 23
- KNMG (Royal Dutch Medical Association)
 - Guideline for Palliative Sedation 154–5, 158, 159–60, 208, 210, 218, 220, 221;
 - administration of fluids 171–2, 178, 179; administration of palliative sedation 173–4, 177–8; decision-making process 165–71, 172, 175–7, 180–1; defining practice of palliative sedation 161;
 - discussion with patient and/or representative 169–71, 175–6;
 - existential suffering 162–3; familiarity with 175, 181; impact of 174–8, 181;
 - indications and preconditions 161–5, 168, 173; input of consultant mandatory 164, 168–9, 179; intermittent sedation 164, 171; life expectancy 163–4; normal medical practice: sufficient justification 178–80; nurses 166, 173–4, 175, 176, 177, 179–80; requirement to consult palliative specialist 164, 167–9, 179;
 - requisite prognosis 163–5; two-week period 163, 164, 165, 179, 205
- Korea Declaration 22, 111
- Kübler-Ross, Elizabeth 18, 44, 84
- labour law: caregiver's leave 189, 220
- Landa, Michel 184
- Larkin, Philip 1
- lasting and unbearable suffering: euthanasia in Netherlands 51–4, 80
- Latin American Association of Palliative Care 21
- Latvia 22
- Law n° 2005–370 (Leonetti's law)
 - 191–6, 200, 207, 213, 221; advance directives 193, 194, 195; developing palliative care capacity 196; double effect reasoning 195, 200, 210, 213; patient autonomy 193–5, 197, 198, 199;
 - withholding and withdrawal of medical treatment 192–3
- Law n° 2016–87 (Claycs-Leonetti law)
 - 198–214, 221; administration of ANH 208–9, 210, 212; administration of continuous deep sedation 209;
 - advance directives 201, 206, 211, 213;
 - deciding to stop treatment 205–6;
 - decision-making process 206–7; defining continuous deep sedation 202–3;
 - euthanasia laws 211–12; euthanasia and specialist palliative care 210–11, 219, 221; existential suffering 204; impact of 212–13; indications and preconditions 203–6, 210; requirement to consult palliative specialist 207; requisite prognosis 205; Sicard report: *Penser solidairement la fin de vie* 198, 199–200, 202, 211, 214; substance of 200–2
- legal and ethical justification of specialist palliative care practices 57–79; double effect *see separate entry*; palliative care without ANH 70–9
- legal framework for palliative care in England and Wales 120–38, 152–3, 219–20, 221; choice 124–5; Clinical Commissioning Groups 127, 130–1, 132, 133, 135; EAPC 149–52; emerging legislative response 133–8, 152; Five Priorities for Care 130; legislative approach 137; Liverpool Care Pathway, demise of 128–30, 152; NICE, contribution of 131–3; planning and commissioning of services 130–1; 'postcode lottery' 121, 131, 136; shaping palliative care provision and development 120–6; standard setting function of General Medical Council 126–8
- legal framework for palliative care in France
 - 126, 182–214, 220, 221; 'Circulaire Laroque' 184–5; conflict of autonomy and medical paternalism 184, 186, 187–8, 202, 213; decision-making in

- practice: pre- and post-Leonetti 196–8;
evolving social and legal paradigm
183–8; first palliative care unit (USP)
185; Law n° 99–477 188–9, 199; Law
n° 2002–303 (Kouchner's law) 189–90,
199, 200; Law n° 2005–370 (Leonetti's
law) *see separate entry*; Law n° 2016–87
(Claeys-Leonetti law) *see separate entry*;
person of confidence 190, 192, 193,
194–5, 197, 206–7; refusal of treatment
182, 187, 189, 190, 192, 193–4,
199–200, 205–6, 210, 213
- legal framework for palliative care in Ireland
138–49, 152–3, 219, 220, 221;
diverging standards and practice 145–6;
EAPC 149–52; framework for palliative
care development 139–40; Irish
Association of Palliative Care 21, 139,
146–9; Irish Medical Council guidance
140–2, 145, 146; national audit (2008)
145; Nursing and Midwifery Board of
Ireland guidance 142–5, 146;
patient-centred approach 141, 144
- legal framework for palliative care in
Netherlands 154–81, 206, 220;
development of palliative care 155–8;
duty to care 155–6; guidelines on
specialist palliative care 158–60, 181;
KNMG (Royal Dutch Medical
Association) Guideline for Palliative
Sedation *see separate entry*; professional
standards 160
- LGBTQ community 222
- life expectancy 163–4, 168
- life, presumption in favour of prolonging 126
- life, right to 10
- list of steps: to clarify intention in
administering sedative drugs 70; in
decision-making process 148
- listening 99
- Liverpool Care Pathway (LCP) 128–30,
132, 152
- Luxembourg 8
- Malta 22
- Mangan, Joseph 59
- Marie Curie nurses 31
- Marymount Hospice (Cork) 16, 20
- medical specialty 30, 152, 186; recognition
of palliative medicine as 22–3
- medication management 32
- mental health 39; *see also* existential
suffering
- midazolam 40, 62, 178, 209
- Mill, J.S. 83, 84–5
- mobile palliative care teams 185
- Monod, Jacques 183
- morality 66; *see also* ethics
- morphine 40, 41, 49, 67, 68, 106, 111,
123, 177–8
- motor neurone disease/amyotrophic lateral
sclerosis 23, 164
- Mount, Balfour 19
- multidisciplinary approach/practice 4, 7,
20, 25, 127, 129, 146, 148, 149, 185,
206, 216, 222; decision to administer
sedation 64, 70; KNMG (Royal Dutch
Medical Association) Guideline 173
- Mumbai Declaration 112
- murder: identifying requisite intention
54–7; acting with variety of intentions
56; actus reus 54, 74–5; double effect
57, 67–8; indirect intention 54–5; mens
rea 54–7, 74
- murder and failure to provide nutrition and
hydration 74–6, 92
- natural law 59
- negligence 219
- Netherlands 3, 80, 219; ANH, sedation
without 71, 74, 158–9, 163, 165; due
care criteria 50–1; euthanasia: law and
practice 49–54, 156, 157, 158–9, 163,
176, 180, 219, 220; hospices 156–7,
158, 175; hospitals 27, 157, 158,
175; intention when administering
continuous palliative sedation 63;
KNMG (Royal Dutch Medical
Association) Guideline for Palliative
Sedation *see separate entry*; lasting and
unbearable suffering 51–4, 80; legal
framework for palliative care in *see
separate entry*; patient autonomy in
withholding and withdrawal of ANH 74;
physician-assisted suicide 8, 49, 50, 51,
53, 176, 181
- New Zealand 27
- non-cancer patients 135, 164, 168; restricted
care for 24; *see also individual diseases*
- non-discrimination 100, 113, 114, 117
- Northern Ireland 120, 132
- Norway 22, 27
- nursing homes 28, 31–2, 157, 158, 175
- Nursing and Midwifery Board of Ireland
139, 142–5, 146; nurses with
prescriptive authority 144–5; older
people 143–4; respect for dignity of
person 142–3

- obstinacy, unreasonable 192, 202, 206, 212
 occupational therapists 28
 omissions and acts dichotomy 3, 54, 74–6, 78
 opiates 40, 123; morphine 40, 41, 49, 67, 68, 106, 111, 123, 177–8
 opioids 19, 40–1, 101, 111, 114–15, 222; Cape Town Declaration 22; hastening of death and 41, 42–3, 61, 69; inadequate use of 117; NICE guidance 132, 133; opiates *see separate entry*; toxicity 42
 Our Lady's Hospice (Dublin) 17
 oxycodone 40
- paediatric palliative care 3, 112, 222
 pain 51, 113, 131, 156, 159, 186, 189; assisted-suicide and euthanasia and fear of 176, 211; capacity and severe 94; Claeys-Leonetti law in France 202, 203; duty of care 136; EAPC recommended framework 151; IMC guidance 141–2; NICE guidance 132, 133; right to pain relief/management 105–6, 109, 110, 111, 115, 190, 218; sedation scales 66; total 18, 25, 39
 palliative care approach 6
 palliative care, right to 82, 109–17, 218–19
 paternalism 127, 170, 182, 183–4, 186, 187–8, 202, 213
 percutaneous endoscopic gastrostomy (PEG) tube placement 73
 persistent vegetative state 75–6, 100
 physical/bodily integrity 96; ANH by way of nasogastric tube 77; right to 11, 81, 82, 106–9
 physician-assisted suicide 8–9, 154, 210, 211–12, 221; Netherlands 8, 49, 50, 51, 53, 176, 181
 physiotherapists 28
 place of death 29–30, 124, 135, 158; factors influencing 30; home 9, 29, 31, 86, 158, 175, 178, 184; hospital 9, 27, 29, 158
 Poland 22, 27
 population 2, 29
 Portugal 22, 27
 Prague Charter 22, 111–12
 private and family life 81, 91, 100, 106–9
 proportionality 58, 65–6, 70, 96, 190, 192, 193, 209, 210
 psychological suffering *see* existential distress
 public health nurses 28
 quality of life 6, 20, 61, 83, 99, 196; artificial hydration 45; pain and symptom management 122; for patients and their families 83, 86, 114, 181
- Raijmakers, N.J.H. 45, 46, 72, 149
 records 125, 150, 193; confidentiality of 190; document clearly and fully 70
 reduction in consciousness 148, 161, 167; double effect 61–2, 65, 66, 68–9, 216
 referral criteria 24, 26; community setting 30
 refractory symptoms 38–40, 51, 80; definition 38, 147, 161–2, 204; delirium 39, 42, 73; EAPC recommended framework 150–1; existential distress 39–40, 52–3, 54, 84, 147, 151, 162–3, 204; flow diagram to assist in identifying 162; forms of distress 39, 162; France: Claeys-Leonetti law 203–4, 206, 207, 210; General Medical Council guidance 128; informed consent 89; Irish Association of Palliative Care 147; Irish Medical Council guidance 142; KNMG (Royal Dutch Medical Association) guidance 161, 161–3, 164, 165, 168, 172; monitoring to ensure controlled 64; Nursing and Midwifery Board of Ireland guidance 145; reduction in consciousness 69, 161; subjective element 162, 204; titration of sedative drug until adequate relief from 66; vomiting 39
 refusal of all forms of nutrition 93
 refusal of treatment 66, 86, 89–91, 94, 216–17; advance decisions 97; artificial nutrition and hydration 71, 73–4, 97–8, 193, 199; France 182, 187, 189, 190, 192, 193–4, 199–200, 205–6, 210, 213; Ireland 90–1, 97–8, 141; United Kingdom 90, 92
 relational autonomy 87
 religion 16–17, 26, 58–9, 79, 90, 127, 209
 research, emergence of culture of 17–18
 respite care 26
 restlessness 39, 53
 right to palliative care 82, 109–17, 218–19; advocating for 110–12; domestic law 115–17; international law 112–15
 Romania 22, 117
 Rousseau, J.-J. 187
 Royal Victoria Hospital Montreal 19
 Rozenheuvel hospice 156
 Russia 117

- St Christopher's Hospice 18–19; home care services 30–1
- St Joseph's Hospice (London) 17–18
- Salmanticenses 58
- Saunders, Dame Cicely 17–18, 31, 44, 120
- Scotland 120, 132; Scottish Partnership for Palliative Care 20
- sedation, palliative 3, 6, 9, 11, 33–8, 104, 195, 200; abuse, potential for 151; advance healthcare directive 74; autonomy 62, 88, 89, 93, 170, 180, 181, 218; continuous deep sedation 34, 71, 91, 150–1, 175, 176–7, 201, 202–7, 208, 209, 210, 211, 212–14; deep sedation 34, 91, 201; definition 36–8; dignity 99; double effect *see separate entry*; drugs used 40–4, 62, 132, 173, 177–8; EAPC recommended framework 150–2; euthanasia and 11, 37, 39, 43–4, 48, 54, 57–70, 128, 158–9, 163, 165, 169, 172, 176–7, 179, 180, 195, 202, 206, 210–12, 213, 214, 215–17, 219, 220; General Medical Council guidance 128; hastening of death 41, 42–3, 54, 61, 62, 63, 64, 66–7, 68, 69, 151, 205; informed consent 88–9, 169–71; intention 37, 38, 198, 216; intermittent sedation 161, 164, 171, 204, 205; Irish Association of Palliative Care 21, 147–8; Irish Medical Council guidance 141–2; KNMG (Royal Dutch Medical Association) Guideline for *see separate entry*; level of sedation 41–2, 151; list of steps in decision-making process 148; list of steps to clarify intention 70; mean survival time 72; mild sedation 33; Nursing and Midwifery Board of Ireland guidance 144–5; process rather than single decision 64, 177, 179, 216; refractory symptoms *see separate entry*; respite sedation 33–4, 39, 151; terminology 34–8, 44; toxicity 41–2; without artificial nutrition and hydration 70–9, 80, 158–9, 163, 165, 171–2, 178, 179, 216–17
- self-determination 29, 73, 82, 84, 90, 143, 194, 211, 213
- separation of powers 115, 116
- silence, culture of 25, 44
- Slovakia 22
- social contract 187
- social death 62
- social embeddedness 85–6, 87, 180
- social workers 28
- Société Française d'Accompagnement et des soins Palliatifs (SFAP) 185–6, 201, 203–4, 205, 206, 207, 208, 209, 210, 212–13, 214, 221
- Somerville, Margaret 110
- South America 19
- south-east Asia 28
- speech and language therapists 28
- statistics and terminology 36
- Sweden 34, 71
- Switzerland 34, 71
- Taiwan 27
- Tajikistan 117
- terminology 4; care pathway 128; degrading treatment 102; end-of-life care 7; euthanasia 7–9; inhuman treatment 192; palliative care 4–6, 83, 99, 188–9; sedation 34–8, 44; specialist palliative care 6–7
- titration of drugs 133, 151; proportionality 66; respite sedation 33; toxicity 42
- torture 101
- total pain 18, 25, 39
- trajectory, disease 24, 26, 164; community setting 29; euthanasia in Netherlands 51; existential distress 39; informed consent 89; palliative care in Netherlands 164, 170, 180; unpredictable non-cancer 24
- trespass against the person 88
- trust 87; patient–doctor relationship 86, 187–8, 189
- tuberculosis 16, 17
- Turkmenistan 117
- Twycross, Robert 20
- Ukraine 117
- unbearable suffering 51, 52–4, 162
- United Kingdom 3, 9, 15–16, 25, 46, 49, 105, 117, 119–20; advance care directives 93, 96–7; ANH, withdrawal of 75–6; autonomy 73, 82, 90, 91–3, 124, 127, 135; capacity 94–7; community setting 29, 30–1; double effect in courts 66, 67–8, 69; EAPC recommendations 149; emergence of modern palliative care 19–20, 22; health, right to 115; home deaths 9, 29; hospices 17–19, 26, 30–1, 121, 131; hospitals 20, 27, 131; House of Commons Health Committee 124–5, 130, 135; House of Lords Select Committee on Medical Ethics: double effect 64–5; legal framework for palliative care in England and Wales *see*

262 *Index*

- separate entry*; murder: identifying
requisite intention 55, 56; National
Council for Palliative Care 20, 134;
NHS Constitution 124, 132; palliative
care, right to 116–17; population 2;
‘postcode lottery’ 121, 131, 136; refusal
of treatment 90, 92; sedation 34, 128
- United States 22, 73, 168; ANH: medical
treatment 77; double effect in courts 66;
hospitals 27; New York State 126, 218;
physician-assisted suicide 8; research 18
- Uzbekistan 117
- World Health Assembly 112
- World Health Organization (WHO)
18–19, 105, 207; definition of palliative
care 5–6, 83, 99, 155; essential drugs
114; opioids 40–1