Chronic Heart Failure
Model of Care
Contents

Contents 3

Preface 6

Foreword 7

Acknowledgements 8

1. Executive Summary 10

2. Key recommendations for standards of care 15

3. Background 16
   3.1 The increasing burden of chronic heart failure (CHF) 16
   3.2 Implications for Lewisham ................................................................. 16
   3.3 The incidence and prevalence of CHF in Lewisham .......................... 17
   3.4 Admissions for heart failure .............................................................. 18
   3.5 Mortality .......................................................................................... 18

4. Diagnosis and classification of chronic heart failure (CHF) 20
   4.1 Definition of CHF: clinical syndrome and pathophysiological state 20
   4.2 Diagnosis .......................................................................................... 21
   4.3 Causal diagnosis ............................................................................. 22
   4.4 Classification of CHF ...................................................................... 23
   4.5 Acute heart failure (acute HF) .......................................................... 24
   4.6 Factors affecting patient outcomes .................................................. 24
   4.7 Recommendations: diagnosis and assessment of CHF .................. 25
   4.8 Suggested indicators: diagnosis and assessment of CHF ............... 25

5. Management of CHF 26
   5.1 Key principles of management .......................................................... 26
   5.2 Hospital presentation ...................................................................... 26
   5.3 Emergency department ................................................................... 27
   5.4 Ward admission ............................................................................... 27
   5.5 Discharge plan ................................................................................ 27
   5.6 Home arrangements ....................................................................... 27
   5.7 Programme (nurse) co-ordinator ..................................................... 28
   5.8 The role of the GP .......................................................................... 28
   5.9 The role of the heart failure specialist nurse ................................. 28

6. Pharmacological management of CHF 29
   6.1 Diuretics ........................................................................................ 29
   6.2 Angiotensin converting enzyme (ACE) inhibitors ........................... 29
   6.3 Angiotensin receptor blockers (ARB) ............................................. 29
   6.4 Vasodilator drugs and nitrates ....................................................... 29
   6.5 Digoxin ............................................................................................ 30
   6.6 Spironolactone ............................................................................... 30
   6.7 Beta adreno-receptor blocking agents ......................................... 30
   6.8 Levels of evidence for the effectiveness of treatments ................ 30
   6.9 Levels of evidence for effectiveness of drug treatments .............. 31
   6.10 Dosages ......................................................................................... 32
   6.11 Adherence ..................................................................................... 32
   6.12 Upward dosage titration ............................................................... 32
   6.13 Combination therapy .................................................................... 32
   6.14 Recommendations: pharmacological management of CHF .......... 33
   6.15 Suggested Indicators: pharmacological management of CHF ....... 33
   6.16 Summary of key findings ............................................................. 34
## Appendices

Appendix A: Classification of functional status ................................................................. 58
Appendix B: NH&MRC designation of levels of evidence .................................................. 60
Appendix C: Tools for assessing functional status and outcomes ................................. 61
Appendix D: Integrated Care Pathway for Heart Failure ................................................... 63
Appendix E: Guidelines for diagnosis and management of Heart Failure ....................... 64
Appendix F: Referral Pathway for Specialist Palliative Care ........................................... 67
Appendix G: List of figures ................................................................................................. 69
Appendix H: List of tables ................................................................................................. 69

## References

70
Preface

This report presents an overview of chronic heart failure (CHF) and a discussion of the major problems recognised to confront all who are concerned with the management of the disease, namely patients, carers and health care providers. It addresses how these problems are being approached throughout industrialised countries, directing attention towards those interventions and supports which have now been demonstrated to be effective in the management of CHF patients.

Recommendations are made about how to improve standards of care, based upon published scientific evidence. Perceptions of practitioners regarding deficiencies in current services are also referred to, together with reports of strategies which have been used to overcome weaknesses across the current health service system. Indicators to use in assessing the delivery of services and patient outcomes are suggested.

Key recommendations for standards of care

Chapter 2 presents the report’s key recommendations for standards of care of patients with CHF, which are as follows:

All patients presenting with CHF require an accurate clinical diagnosis and confirmation of that diagnosis.

All patients with established CHF require:

- seamless progression through each stage of education, management and support
- optimal pharmacological management, directed by national and international guidelines
- non-pharmacological management in the form of an integrated management programme (CDM), supported or managed by a heart failure (nurse) co-ordinator
- a continuing programme of activity and exercise based upon walking and maintenance of muscle strength for activities of daily living.

All patients and carers require education and support in achieving and maintaining a programme of self-care.

Any patient with any form of heart disease may progress to CHF. Prevention of CHF is possible by following guidelines appropriate to the underlying condition.

Each of the recommendations and standards of care is covered in some detail in the ensuing chapters and appendices.
Foreword

Dr Ben Essex MBBS, MSc, FRCGP, FRCP

The Cardiology Clinical Panel should be congratulated for producing this valuable document which describes an integrated model of care for patients with chronic heart failure. This is an evidence based consensus of best practice aimed at patients, carers, and professionals working together to improve all aspects of care.

The model is comprehensive and covers the total care pathway. It includes detailed information about diagnosis, assessment, management, and follow-up in different settings including home, community, general practice and hospital. It will be of great practical value to doctors and nurses working in all these settings.

This model also includes the very neglected area of palliative care for patients with chronic heart failure. The importance of self-care by patients and carers is highlighted and the model outlines how this can be achieved.

This document makes an overwhelmingly convincing case that effective management is best achieved by an integrated care model. It is essential for doctors, nurses and commissioning working groups to have access to this document as it will help to improve shared care between professionals and patients and carers at all settings. It will also help to commission appropriate services for this vulnerable and neglected group of patients. Those who commission care for patients with chronic heart failure will find this document of great value. It forms the basis for the development of a service level agreement which covers all care pathways, is comprehensive and evidence based, and contains measurable goals and outcomes.

It should be circulated to relevant groups involved in providing care, further professional development, and commissioning of services for patients with chronic heart failure. This valuable document could form the basis for improving standards of long term care at all stages of this distressing disease.
Acknowledgements

The authors wish to thank the following for their contributions:

- Professor Abe Guz, Emeritus Professor of Medicine, National Heart and Lung Institute
- Professor Maurice Craft, Lay Representative
- Mr Peter Kettle, Lay Representative
- Dr Stefan Karwatowski, Consultant Cardiologist, Bromley Hospital
- Dr Gordon Jackson, Consultant Cardiologist, Lewisham Hospital
- Dr Stephen Jenkins, Consultant Cardiologist, Guy’s and St Thomas Hospital (ret’d)
- Dr Sanjay Sharma, Consultant Cardiologist, Kings College and Lewisham Hospitals
- Dr Brian Fisher, General Practitioner
- Dr Ray Vella, General Practitioner
- Dr Nada Lemic, Director of Public Health, Bromley Primary Care Trust
- Dr Chris Watts, Director of Public Health, Lewisham Primary Care Trust
- Mr Nickos Efthymiou, Pharmaceutical Advisor, Lewisham Primary Care Trust
- Ms Pippa Agnew, Heart Failure Specialist Nurse
- Ms Kathy Marshall, Nurse Consultant, Lewisham Hospital
- Ms Sara Nelson, Associate Director, SEL Cardiac Network

This report has been produced under the auspices of the Cardiology Clinical Panel and is based on the following publications:

- The American College of Cardiology Guidelines for the evaluation and management of chronic heart failure
- The European Society of Cardiology Guidelines for the diagnosis and management of Chronic heart failure in the Adult
- The National Institute of Clinical Studies Diseases Management Working Party report on heart failure
- Bromley and Lewisham Primary Care Trusts Guidelines on the management of chronic heart failure in primary and community care

We are particularly grateful to the American College of Cardiology, the American Heart Association and the Victorian Government Department of Human Resources for permission to reproduce in part their respective reports on the management of heart failure.
1. Executive Summary

Background

As discussed in Chapter 3, CHF is a major source of continuing disability, particularly in older people, both male and female. It contributes to frequent emergency department attendances and urgent hospital admissions, representing one of the greatest demands for hospital beds. After discharge from hospital, early readmission is required within one month for 20% of patients. The death of 50% of patients is expected during the ensuing three years following first presentation with an episode of an acute heart failure (CHF). The problem is increasing with an ageing population and costs associated with CHF are considerable. The prevention or more effective control of episodes of acute HF should lead to better outcomes for patients and a significant decrease in health care costs.

Diagnosis and classification of CHF

Chapter 4 describes CHF as a complication and sometimes pre-terminal state of heart disease, which has often been of long standing. The diagnostic and other difficulties facing medical practitioners are discussed and features of recent guidelines are outlined. Appendices A to E provide further details about the classification of CHF, levels of evidence for the effectiveness of treatment, and a summary of the guidelines produced by the Cardiology Clinical Panel, Lewisham Primary Care Trust.

All patients with CHF:

- Presenting with an episode of CHF or acute HF require confirmation of diagnosis by clinical assessment and investigation
- Assessment of severity of CHF by symptoms (e.g. NYHA functional class or other)
- A diagnosis of the underlying cause of CHF
- Assessment of left ventricular function by echocardiogram
- Patients presenting with an acute HF episode require exploration of precipitating cause/s of that episode, and
- Require documentation of significant co-morbidity.

Key principles of management

In Chapter 5, key principles of the management of CHF patients are set out from the time of hospital admission to follow-up after discharge from hospital and management in the community. In summary, it is recommended that all patients presenting with CHF require:

- Confirmation of an accurate clinical diagnosis
- Seamless progression through each stage of education, management and support
- Optimal pharmacological management, directed by national and local guidelines
- Non-pharmacological management in the form of a Chronic Disease Management (CDM) programme, supported or managed by a heart failure (nurse) co-ordinator
- A continuing programme of activity and exercise based upon walking and maintenance of muscle strength for activities of daily living, and
- Education and support in achieving and maintaining a programme of self-care.
- Any patient with any form of heart disease may progress to CHF. Prevention of CHF is possible by following guidelines appropriate to the underlying condition.
Pharmacological management

Chapter 6 covers pharmacological interventions, based largely upon national and international guidelines. Pharmacological treatments have advanced greatly in the past decade, with several therapeutic options demonstrated in clinical trials to reduce mortality, acute events and disability markedly. Scientific literature reviews and large randomised prospective clinical trials now present strong evidence for best practice in the pharmacological management of patients. While the importance of proper pharmacological management of CHF patients is now being recognised and information about appropriate medications widely disseminated, there is a definite need for more education among both general practitioners and specialist physicians.

Acute events continue to occur at the same rate as before, despite recent advances. Inadequate, even inappropriate, medication is often still being prescribed, indicating that evidence is only slowly extending into clinical practice. However, it is acknowledged that prescription of appropriate drugs is sometimes problematic because of the complex nature of the disease and the presence of co-morbidities among many CHF patients. Studies producing evidence of the effectiveness of particular medications usually excluded older patients with multiple co-morbidities.

Non-adherence to recommended regimens is another major problem and remains high among CHF patients, many of whom are old, have multiple co-morbidities, impaired memory and impaired cognitive function. Carers can play a vital role in ensuring adherence to prescribed medication.

It is recommended that CHF patients:
- who have symptomatic or other evidence of congestion should receive diuretic treatment
  - with loop diuretic if an acute episode
  - with loop or thiazide diuretic if not an acute episode
- receive treatment with an angiotensin converting enzyme (ACE) inhibitor unless contraindicated
- who are unable to take ACE inhibitor should be considered for treatment with angiotensin receptor blocker (ARB)
- treated with ACE inhibitor or ARB should be also treated with a beta-blocker unless contraindicated
- who are symptomatic should be treated with digoxin unless contraindicated
- with severe CHF, despite appropriate dosage of ACE inhibitor and diuretic, should receive spironolactone
- have additional medication to control the causes of CHF (e.g. lipid-lowering agents, aspirin, hypotensive agents as indicated)
- at time of institution of treatment with ACE inhibitor, should have renal function assessed
- receive a low dosage of selective ACE inhibitor as a start and be titrated upwards to the dosage used in clinical trials, if possible
- receive a low dosage of selected beta-blocker as a start and be titrated upwards to dosage used in clinical trials, if possible
- have standing blood pressure recorded, additional to lying or sitting
- who have atrial fibrillation (AF) should be considered for treatment with aspirin or warfarin
Non-pharmacological management

To achieve maximal benefit from effective interventions, multi-disciplinary care is required in addition to pharmacological treatment. Non-pharmacological interventions provide support and education for both patient and carer. They may include telephone calls or home visits by a health care provider, referral to an exercise or other community programme, and review by a specialist, either in individual practice or at a hospital-based outpatient HF clinic or chronic disease management unit.

The value of non-pharmacological programmes of integrated care is less well recognised. In consequence, Chapter 7 of this report presents in some detail an analysis of the now very strong evidence for benefit from integrated care or management. Non-pharmacological interventions have been shown to reduce the occurrence of acute events and hospital admissions significantly. These improvements are probably associated with a greater understanding of the condition and improved health care by patients, better adherence to regimens, and support from carers.

Scientific literature review demonstrates from repeated, although small studies, that multi-disciplinary care with education programmes for patients and carers favourably affects outcomes. Adequate follow-up and support generate significant additional benefits. However, there remain significant deficiencies in the evidence base of what works best in prevention of recurrent episodes of acute HF.

Personal education of patient and family is imperative for optimising the patient’s capacity to manage their condition. This education should be delivered while the patient is in hospital and reinforced following discharge and include:

- Education should be interactive with full participation of patient/carer, questions answered, and explanation and reasons given for each therapeutic intervention
- Questions should be asked to ensure that patients and carers understand advice
- Formal discharge plans should be arranged with assurance of all appointments and procedures
- Telephone calls should be made to identify those needing further assistance, especially a home visit
- Home visits should be undertaken early, preferably within one week of discharge, to patients identified at risk of relapse with reinforcement of advice given during home visits
- Follow-up by telephone or visits should be arranged for missed appointments
- Patients have GP appointments confirmed
- Patients have referral to cardiologist or physician (individual or in clinic)
- Patients understand need for adherence to medication with consideration of dose and compliance aids
- Patients should understand the significance of weight gain (greater than 1.5kg in one day or 2kg in two days)
- Patients should cease smoking
- Patients should be aware of risks of infection, particularly respiratory, and have annual influenza vaccinations and 3-5 yearly pneumococcal immunisation.

This information should be reinforced with simple educational materials such as booklets, pamphlets, fact sheets, videos, tapes etc.
Exercise programmes

Exercise training programmes for CHF patients are discussed in Chapter 7. The physical and psychosocial benefits of exercise for CHF and other cardiac patients are widely acknowledged. Attendance at a group programme following discharge from hospital also provides an opportunity for further education of patients and carers regarding medication and other aspects of their rehabilitation. It is recommended that:

- A dynamic (aerobic) exercise programme, starting at low level and slowly increasing in duration, frequency, intensity and of preferably daily activity should be devised for each patient
- The level of activity should be supported by assessment of progress through verbal report, observation and, if possible, a formal measurement of walking capacity (e.g. Six Minute Walk Test)
- Strength training, with use of muscle groups against resistance (similar to many activities of daily living), should be incorporated into the exercise programme
- Long term support, enquiry and supervision are required to assure adherence to home activity and exercise
- Formal group exercise training programmes are recommended where there are heart failure management programmes
- Group exercise may be limited to patients with CHF or may be grafted on to a mainstream cardiac rehabilitation exercise programme, and
- Home exercise is important for all CHF patients, especially older patients, those without transport and those from culturally and linguistically diverse backgrounds who may not participate in group programmes.

Staffing and facilities in integrated disease management programmes

Chapter 7 also describes the multidisciplinary team and discusses the roles of each team member. CHF patients require input from several different health care providers. Included in the multi-disciplinary team are a nurse, physiotherapist, occupational therapist, social worker, dietician, pharmacist, cardiologist or general physician, general practitioner, psychologist and others. Above all, an efficient and committed case manager or programme co-ordinator is required to ensure good linkages between hospital and community so that patients receive a continuum of care from hospital admission to their return into the community. While each health care provider in the team has specific expertise and training, many tasks may be shared. The following recommendations are made:

- A co-ordinator is required for effective non-pharmacological management of CHF patients
- Other health professionals and community care staff should be available, as required. Some have special expertise appropriate to patients with specific difficulties (e.g. respite care worker, community care services)
- The co-ordinator requires good access to the regional cardiologist/physician or clinic and hospital support
- The co-ordinator needs to establish bi-directional interactions with local GPs
- Special training of potential nurse co-ordinators is required, through courses, to expand rapidly the accessibility of the knowledge base required for the specific nature of the work
- Administrative and other supports are required, sited in the community centre or hospital through which the integrated management programme is delivered.
Self-care

As discussed in Chapter 8, comprehensive education of patients and carers is essential for management of CHF. Patients and carers need to understand and embrace the following recommendations concerning self-care:

- Undertaking daily recording of weight
- Response to weight gain greater than 1.5 kg in 24 hours or 2.0kg in 48 hours
- Response to weight loss
- Limitation of fluid intake to 1.5 litres per day (2.0 litres per day in hot weather)
- Establish pattern of best timing of diuretic medication and of drugs used, in consultation with their GP
- Understanding of the need for long term medication rather than course of treatment
- Control of total caloric intake, persistence of saturated fat restriction
- Salt restriction through no added salt at table nor in cooking, plus avoidance of highly salted foods
- Persistence with activities (walking and activities of daily living) despite induction of dyspnoea with attempt to be active to level of awareness of breathing (not breathlessness) at least half an hour per day
- When in doubt about any aspect of management or behaviour, ask.

Palliative care

While Chapter 9 of this report addresses the ultimate development of the need for terminal or palliative care, its importance is recognised by all health care providers caring for CHF patients. Unfortunately, this aspect of the management of patients with CHF has not been adequately investigated and much research remains to be undertaken. It is recommended that:

- The principles of palliative care should be applied to patients with advanced CHF similar to those appropriate for patients dying of cancer
- Mechanisms for support from carers, community groups and health professionals should be developed, and
- Patients with end stage CHF should be assessed by a health professionals with a working knowledge of supportive and palliative care. If death is likely or imminent, then patients should be assessed by a palliative care team to generate either consultative advice regarding patient management or continuing palliative care.

Confounding problems

Chapter 10 reviews the confounding problems affecting management and outcomes arising from psychological, social and environmental factors.

- Perceptions of health care providers
- International scientific literature presents a pattern of management of CHF that is deficient in many areas.
- The deficiencies, oversights, and errors of management appear to be widespread and entrenched in the pattern of medical care of the past.

Many of these problems have been recognised by the Cardiology Clinical Panel and are presented for the purposes of encouraging discussion and finding potential resolutions.
2. Key recommendations for standards of care

The need for defined standards of care and indicators of best practice arises from the complicated management required for patients with CHF. Failure to achieve quality management occurs because of weaknesses or oversights in the delivery of care to patients, or failure of comprehension or adherence to recommended programmes by patients.

The most apparent outcome indicator of failed or sub-standard care is recurrence of acute heart failure with the need for urgent attention, commonly with hospital emergency department attendance and hospital admission. While such crises may be unavoidable in many cases, the cause or causes of acute HF can be identified in the majority of cases. The potential causes have been largely defined and comprehensively reviewed \(^1\)-\(^3\). The management oversights and patient misunderstandings apply to both pharmacological and non-pharmacological treatments.

The basic recommendations for standards of care are summarised below.

These recommendations are developed throughout the text and followed, where appropriate, with a list of suggested indicators which may be used to assess how well standards of care are being met. Those indicators which are considered most important or easy to collect should be chosen for process or outcome evaluation.

**Recommendations for standards of care**

1. All patients presenting with CHF require confirmation of an accurate diagnosis.
2. All patients require seamless progression through each stage of education, management and support.
3. All patients require optimal pharmacological management, directed by national and international guidelines.
4. All patients require non-pharmacological management in the form of an integrated management programme, supported or managed by a Heart Failure (nurse) co-ordinator.
5. All patients require a continuing programme of activity and exercise based upon walking and maintenance of muscle strength for activities of daily living.
6. All patients and carers require education and support in achieving and maintaining a programme of self care.
7. Any patient with any form of heart disease may progress to CHF. Prevention of CHF is possible by following guidelines appropriate to the underlying condition.
3. Background

3.1 The increasing burden of chronic heart failure (CHF)

CHF currently affects between 2,200 and 3,800 patients, in Lewisham, with about 225 new cases diagnosed annually. On average, about 250 patients per year are admitted to hospital with a primary diagnosis of CHF. CHF accounts for 2% of all hospital deaths.

The major factor leading to CHF is older age. In the United Kingdom, the average life expectancy continues to rise and for females is now 82 years and for males 76.6 years. Much of the survival into older age is a result of advances in the medical care of those with heart disease, particularly following acute myocardial infarction. There has also been a significant improvement in life expectancy of those receiving treatment for hypertension. Medical and surgical treatment of other causes of heart disease (rheumatic heart disease, congenital heart disease and cardiomyopathy) also prolong life and contribute to the increasing occurrence of CHF in older age.

Of patients who present with CHF, 50% are dead within three to four years. Hospital stay, which was averaging eight days a few years ago, has now been reduced to approximately six days. Importantly, after discharge from hospital, unplanned readmission within 28 days is as high as 20% for CHF patients.

The cost of a single hospital admission in Lewisham is currently approximately £3,000. Repeated admissions are common, as are attendances for acute management in emergency departments, followed by a return home within 24 hours. The reasons for attendance at emergency departments and for readmission are quite well defined and most are considered preventable or controllable. However, management approaches demonstrated to be beneficial in studies are commonly poorly executed by patients, carers and health professionals. Thus, acute episodes of CHF commonly occur, precipitating patients into a need for urgent care. Despite pharmacological advances in the care of CHF, there remain common oversights in management.

More effective management of patients with CHF provides for significant benefits to patients and their families. These may include increased life expectancy, reduced hospital admission, retention of income and employment amongst those in the workforce, minimisation of disability and dependency, with consequent improvement in quality of life of patients, reduction or delay of interventions and a decrease in deaths.

Improved management models also provide for more effective use of costly resources through:

- Reduced emergency department attendance
- Reduced hospital admission
- Reduced days in hospital
- Reduced medical attendances
- Improving prescribing habits
- Delivery of improved community services
- Improved adherence by patients to recommended regimens.

3.2 Implications for Lewisham

The Chronic Heart Failure Model of Care is directed towards reducing the load on emergency departments and hospital acute care beds. It is recognised that these
pressures could be reduced through developing continuum of care regimens whereby care is improved at all levels outside hospitals to avoid emergency attendance and admission to hospital. In Lewisham, CHF was the tenth most common diagnosis at hospital admission, with an average of 750 admissions per year at local acute hospitals. About 75% of these patients were aged over 65 years. CHF has the highest admission volume of all conditions in this age group. Average length of stay (ALOS) for CHF patients varies between hospitals from 4.7 days to 8.6 days, with overall ALOS greater than six days.

Thus, with the progressive increase in the number of people over 65 years in Lewisham (currently estimated to be 37,600 from a total population of 149,500), one can expect an ever increasing load upon hospital facilities, unless the quality of care can be improved to prevent acute episodes of CHF.

Methods whereby such improvement may arise are now well defined, confirmed in the scientific literature and published in best practice guidelines. However, guidelines remain poorly implemented at all levels of patient care. Improved implementation has the potential to improve the health status of people with CHF while reducing the avoidable use of hospital facilities.

### 3.3 The incidence and prevalence of CHF in Lewisham

Heart Failure is largely undiagnosed and poorly managed in primary care leading to significant levels of emergency admissions and re-admissions. The prevalence of heart failure in Lewisham is rising, mainly due to an ageing population and improved survival from the main aetiological cause, coronary heart disease. One-year mortality rate is in the order of 40-50% for advanced heart failure and 15-25% for mild to moderate symptoms. Heart failure accounts for approximately 2% of all acute admissions and up to 26% of patients are readmitted within a year of discharge. The cost of admissions for heart failure represented 2.7% of the total budget in 2005/2006 at about £1.7 million.

<table>
<thead>
<tr>
<th>Table 1. Incidence (number of new cases) of heart failure in Lewisham</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Persons aged 25 years and over</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2. Prevalence of heart failure in Lewisham</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Overall</td>
</tr>
<tr>
<td>Age &gt; 65 years</td>
</tr>
</tbody>
</table>
3.4 Admissions for heart failure

Overview of Dataset

To transform Hospital Episode Statistics (HES) dataset from episodes of care level data into case level records for the financial years 2000-2007, a linkage algorithm based on all available variables for matching (date of birth, NHS number, postal code, gender, hospital record number) is used. After this process is completed, a new identification number is assigned to the case-groups, which is not based on any original variable found in the HES.

This dataset enables analysis of hospital utilisation data by individual patient over a 3 year rolling period. In particular, this approach identifies overall hospital utilisation where patients were admitted to more than one hospital. In considering utilisation patterns for patients with CHF, along with their potential to be admitted to more than one hospital, this type of analysis provides a more comprehensive representation of patterns of hospital admission for individual patients than is possible through routine analysis of HES.

For the purpose of this analysis, patients with CHF were defined as those patients who have had at least one emergency hospital admission for which they were assigned a diagnostic related group (HRG) of heart failure and shock. The two HRG codes used were E 18 and E 19. International Disease Classification (ICD) codes I 50 and I 51 were used to identify acute admissions with a primary diagnosis of heart failure.

Incidence and prevalence of heart failure in Lewisham

Table 3. Admissions for Heart Failure as primary diagnosis in Lewisham

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>No of admissions</td>
<td>320</td>
<td>284</td>
<td>253</td>
<td>202</td>
<td>150</td>
<td>232</td>
<td>232</td>
</tr>
<tr>
<td>Cost of admissions @ £ 3000 per FCE</td>
<td>960,000</td>
<td>852,000</td>
<td>759,000</td>
<td>606,000</td>
<td>450,000</td>
<td>696,000</td>
<td>696,000</td>
</tr>
</tbody>
</table>

Figure 1. Admissions for Heart Failure in Lewisham (2000 - 2007)
3.5 Mortality

Routine data in the Public Health Common Data Set does not provide standardised mortality ratios for CHF. In view of this, directly standardised mortality rates (DSR) for CHF were calculated and the rates compared to other PCTs in South London (Figure 2).

A PCT-level Standardised Mortality Ratio is a measure of how likely a person living in that PCT area is to die compared to the standard population of England and Wales.

Figure 2. Age Standardised Mortality rates for Heart Failure in South London
4. Diagnosis and classification of chronic heart failure

4.1 Definition of CHF: clinical syndrome and pathophysiological state

Summarised below are definitions of CHF by major professional bodies, followed by the definition used for the purposes of this report.

The ACC/AHA Guidelines for the Evaluation and Management of Chronic Heart Failure in the Adult\(^1\) discusses the characterisation of CHF as a clinical syndrome, as a symptomatic disorder and as a progressive disorder. It states: “HF is a complex clinical syndrome that can result from any structural or functional cardiac disorder that impairs the ability of ventricle to fill with or eject blood. The cardinal manifestations of HF are dyspnoea and fatigue, which may limit exercise tolerance, and fluid retention, which may lead to pulmonary congestion and peripheral oedema. Both abnormalities can impair the functional capacity and quality of life of affected individuals, but they do not necessarily dominate the clinical picture at the same time. Some patients have exercise intolerance, but little evidence of fluid retention, whereas others complain primarily of oedema and report few symptoms of dyspnoea of fatigue. Because not all patients have volume overload at the time of initial or subsequent evaluation, the term ‘HF’ is preferred over the older term ‘congestive HF’.”

The European Society of Cardiology Task Force Report: Guidelines for the Diagnosis and Treatment of Chronic Heart Failure\(^2\) states: “HF is a pathophysiological state in which an abnormality of cardiac function is responsible for the failure of the heart to pump blood at a rate commensurate with the requirements of the metabolising tissues. This Task Force recommends that there should be symptoms of HF at rest, or during exercise, and objective evidence of cardiac dysfunction (at rest) and (in cases where diagnosis is in doubt) response to treatment directed towards HF.”

Current definition of heart failure

For the purposes of this report, the term “heart failure” means chronic heart failure (CHF) and is a synonym for congestive heart failure. It includes systolic heart failure, diastolic heart failure and combined systolic and diastolic heart failure. These terms are discussed further in the section dealing with echocardiography.

Pathophysiological definition

Cardiac failure is an inability of the heart to deliver blood (and therefore oxygen) at a rate commensurate with the requirements of the metabolising tissues at rest or during light exercise. This leads to characteristic systemic pathophysiological responses (neural, hormonal, renal and others), symptoms and signs.

Clinical definition

Clinically the term ‘HF’ is applied to the syndrome of breathlessness and fatigue associated with cardiac disease. It is often accompanied by fluid retention (congestion), as indicated by an elevated jugular venous pressure and oedema. The clinical diagnosis of HF, therefore, necessitates both the presence of significant cardiac disease and typical symptoms and signs.
4.2 Diagnosis

Symptoms and signs

The major presenting symptoms include shortness of breath and fatigue during little effort or normal activities, waking from sleep with breathlessness, swelling of ankles due to oedema coupled with unexpected weight gain, muscular fatigue, abdominal distension and upper abdominal discomfort due to liver engorgement.

Clinical signs include evidence of pulmonary congestion with moist sounds audible over the lung bases on auscultation, rapid heart action, usually sinus tachycardia, but often with pulse irregularity due to atrial fibrillation or frequent ventricular premature beats. Added 4th or 3rd heart sounds are commonly heard producing a triple or ‘gallop rhythm’ at the apex – (gallop cadence is dependent on associated tachycardia), cardiac enlargement demonstrated by displacement, laterally, of the apex beat. There may also be diffuse or dyskinetic anterior palpable lift inside the apex. Raised venous pressure, most commonly evident in the internal and external jugular veins, is another marker of congestion. In addition to the above, there is usually a history of underlying heart disease. The most common abnormalities include evidence of coronary heart disease, particularly of past myocardial infarction, evidence of hypertension, usually of long-standing and evidence of diabetes (most commonly Type II or adult onset diabetes), usually coupled with obesity. There may be evidence, sometimes equivocal, of past or recent cardiomyopathy or myocarditis, valvular heart disease, either as a cause of, or complication from, myocardial dysfunction, congenital heart disease or pericardial disease.

Secondary features

In addition, there may be evidence of changes arising in individuals who have established CHF. These changes may be both physical and psychological, including generalised muscle wasting from disuse and enforced inactivity, and reduced muscular strength, also due to disuse, which is sufficient to interfere with performance of normal activities of daily living and self care. Increasing weight may occur due to reduced physical activity, independent of weight gain from fluid retention. Decreasing weight can occur from loss of appetite, nausea and abdominal discomfort on eating because of hepatic and gastric congestion. A similar decrease in weight may also occur due to dehydration.

Weight loss may also occur because of a loss of interest in eating associated with psychological depression. Features of psychological depressive illness may include blunted affect, a sense of despair, even hopelessness, and thoughts of death or further life being of little value. Anxiety symptoms and manifestations usually accompany the depressive reaction and may dominate the symptom presentation.

These features are variably discussed in the two sets of the above CHF guidelines 1-3.13.
Tests

Confirmation of diagnosis and its causes is required in each case. This is usually dependent upon tests. Rarely does CHF present without a recognised cause. Hence recognition of an underlying cause is important in establishing the diagnosis.

Radiology

A chest x-ray commonly demonstrates cardiac enlargement and the presence of pulmonary venous congestion.

Electrocardiography

An electrocardiograph helps in defining evidence of past myocardial infarction or persisting ischaemia from coronary heart disease, or of left ventricular hypertrophy from hypertension and may also help in defining arrhythmias.

Blood tests

Urea, creatinine and electrolyte patterns are often disturbed by CHF itself, or by medications to control the CHF.

Serum atrial natriuretic peptide or central (brain) natriuretic peptide may be estimated as markers of elevated atrial pressures, indicating the likely presence of CHF and supplying an additional measure of its severity.

Liver function tests may indicate disturbance of hepatic function.

Lipid levels are required as baseline measures for control of coronary heart disease.

Haemoglobin estimation, with or without full blood examination, is undertaken to exclude anaemia as a cause of the symptoms, or as contributing to the degree of CHF.

Thyroid function tests are performed to exclude both hyperthyroidism and hypothyroidism which may mimic or aggravate CHF.

Echocardiography

Echocardiography is now regarded as a requirement, both in the diagnosis and assessment of CHF, to determine the size and contractility of the ventricle, with measurement of end-systolic and end-diastolic volume from which ejection fraction is also calculated. Further, it assesses the integrity or otherwise of valve function.

Echocardiography is used to determine whether CHF is due to impaired left ventricular contraction (systolic dysfunction) or impaired relaxation (diastolic dysfunction). The former is most commonly found in those with past myocardial infarction or dilated cardiomyopathy as the underlying cause of CHF. The latter is more common in those with long standing hypertension.

These clinical and investigative methods are widely endorsed and reviewed in the scientific literature and in clinical practice guidelines, as referred to above 1-3, 13.

4.3 Causal diagnosis

To have CHF it is necessary to have cardiac disease. Hence the causal diagnosis is also required for categorisation, description and management. In most cases, particularly amongst those with systolic dysfunction, CHF is due to ischaemic heart disease with past
myocardial infarction. Commonly it is due to longstanding hypertensive heart disease, particularly in the elderly and particularly in women where diastolic dysfunction is most commonly found. Rheumatic, congenital, cardiomyopathic and other heart diseases account for a small proportion of patients with CHF. Conduction disturbances may also account for CHF in some patients.

4.4 Classification of CHF

The ACC/AHA categorised impaired ventricular function into four stages. 

Level A High risk of left ventricular dysfunction
This means that HF is not yet present, but that existing heart disease (usually hypertension or ischaemic heart disease) is present and this may lead to left ventricular dysfunction and HF.

Level B Left ventricular dysfunction without symptoms
Left ventricular dysfunction without symptoms is extremely common following myocardial infarction and in long-standing hypertension where systolic or diastolic dysfunction respectively may be present, but symptoms of breathlessness and fatigue are not yet apparent.

Level C Left ventricular dysfunction with current or prior symptoms
Level C deals with CHF as commonly found in practice, with left ventricular dysfunction (systolic, diastolic or mixed). Prior symptoms indicate that the patient, previously presenting with significant symptoms, has had symptoms which responded to appropriate treatment and the passage of time.

Level D Refractory end stage CHF
This refers to advanced CHF, present in those needing palliative care.

For practical purposes, further discussion of CHF in this report concerns Category C. However, it is important to consider Categories A and B in terms of prevention of first presentation with CHF.

Functional class

The New York Heart Association (NYHA) functional class classification has been used for many years and is a simple measure or recording of symptomatic status. 

Table 4 presents the ACC/AHA categories of ventricular dysfunction in abbreviated format, and NYHA functional class. The NYHA functional class is set out in greater detail in Appendix A, together with the alternative Specific Activity Scale.
Table 4. Classification of CHF

<table>
<thead>
<tr>
<th>ACC/AHA category of left ventricular (LV) dysfunction</th>
<th>Status (summarised)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Level</td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>High risk of LV dysfunction</td>
</tr>
<tr>
<td>B</td>
<td>LV dysfunction without symptoms</td>
</tr>
<tr>
<td>C</td>
<td>LV dysfunction with current or prior symptoms</td>
</tr>
<tr>
<td>D</td>
<td>Refractory end-stage CHF</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>NYHA functional class</th>
<th>Status (summarised)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional class</td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>No symptoms with normal effort</td>
</tr>
<tr>
<td>II</td>
<td>Symptoms with normal effort</td>
</tr>
<tr>
<td>III</td>
<td>Symptoms with slight effort</td>
</tr>
<tr>
<td>IV</td>
<td>Symptoms at rest</td>
</tr>
</tbody>
</table>

(Symptoms generally refer to dyspnoea and fatigue. For details, see Appendix A)

The initial assessment of severity may rapidly improve following institution of medication, either at home or with a short period of hospital care. This explains how patients can be categorised as suffering from CHF but, when seen subsequently, may have no symptoms, having reverted to Class I, despite having impaired ventricular function.

4.5 Acute heart failure (acute HF)

It is episodes of acute HF that necessitate urgent medical care. These episodes of acute HF lead to hospitalisation of patients with CHF. Acute HF may appear for the first time, or may appear repeatedly throughout ensuing months or few years prior to death. Usually presentation is with acute pulmonary oedema. This is preceded by recognisable fluid retention, often overlooked.

Causal factors for acute HF have been widely investigated and reported. Of greatest importance is non-adherence to medication and modification of dosage or timing of diuretic regimens. The precipitating factor for acute HF is most commonly failure to take a diuretic because the diuretic interferes with activities expected during the day, and then forgetting to take the diuretic on return home in the afternoon or evening. Under these circumstances pulmonary oedema is likely to occur during the night. This produces a need for urgent medical care, commonly with emergency department attendance and often with hospital admission usually for several days. Response to hospital treatment is usually rapid, with reinstitution and re-evaluation of regimens of care but, as widely reported elsewhere, these regimens are likely to be inadequately administered and supervised.

4.6 Factors affecting patient outcomes

As indicated earlier, 20% of patients are likely to be readmitted within 28 days following first admission to hospital with acute HF. 50% of patients are likely to be dead within three years.

There are many factors affecting adverse outcomes, including:
- non-adherence to medication
- non-adherence to self care regimens
- older age
- more severe CHF
- infection
- arrhythmia
• recurrent myocardial infarction or ischaemia
• pulmonary embolism
• anaemia
• co-morbidity
• treatment of co-morbidity

The severity of CHF, as reflected by ventricular dysfunction, and also by symptoms while taking treatment, is a major marker of adverse outcome.

The older the patient, the greater the risk of disability, dependency and death. As women develop CHF approximately 10 years later than men on average (because of their older age and the later onset of heart disease), women have a worse prognosis than men.

Prognosis, particularly in terms of disability, is partly related to co-morbidity, including chronic obstructive pulmonary disease, arthritis, obesity and diabetes. Treatment of co-morbidity and the effects of such treatment may interfere with the management of CHF itself, for example, the adverse effects of non steroidal anti inflammatory drugs (NSAID), steroidal treatment, neurotrophic medication, beta agonists and other medication.

4.7 Recommendations: diagnosis and assessment of CHF

Table 5. Recommendations: diagnosis and assessment of CHF

<table>
<thead>
<tr>
<th>Patients with CHF or presenting with an episode of acute HF require:</th>
<th>Level of evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>confirmation of diagnosis by clinical assessment and investigation</td>
<td>EO</td>
</tr>
<tr>
<td>assessment of severity of CHF by symptoms (eg NYHA functional class)</td>
<td></td>
</tr>
<tr>
<td>a diagnosis of the underlying cause of CHF</td>
<td></td>
</tr>
<tr>
<td>assessment of left ventricular function by echocardiogram</td>
<td></td>
</tr>
<tr>
<td>documentation of significant co-morbidity</td>
<td></td>
</tr>
<tr>
<td>Patients with an acute HF episode require exploration of precipitating cause/s of that episode</td>
<td>EO</td>
</tr>
</tbody>
</table>

4.8 Suggested indicators: diagnosis and assessment of CHF

Table 6. Suggested indicators: diagnosis and assessment of CHF

1. Proportion of patients with provisional diagnosis of CHF confirmed to have correct diagnosis
2. Proportion of patients with rating of symptom severity (eg NYHA class or other) recorded on admission, on discharge and at follow-up
3. Proportion of patients with underlying cause of CHF established
4. Proportion of patients who have had an echocardiogram during hospital admission or convalescence
5. Proportion of patients with acute HF in whom probable precipitating cause(s) is recorded
6. Proportion of patients with co-morbidity noted in medical record
5. Management of CHF

ACC/AHA Categories C & D

5.1 Key principles of management

For patients with CHF, careful integrated management, both pharmacological and non-pharmacological, has been demonstrated to delay or prevent acute episodes, significantly reduce emergency attendances and hospital admissions, with significant benefits to patients, families, emergency departments and hospital bed loads. To achieve these outcomes, it is necessary to have a continuum of care, extending between hospital and community and into the patients’ homes.

Evidence-based best practice is set out in guidelines 1-3 and appropriate standards are now defined. The clearest evidence arises from pharmacological interventions. Physical interventions, in the form of transplantation, mechanical assist devices, some other surgical interventions and biventricular pacing have been successfully applied to subsets of patients.

Considerable attention has now been directed to non-pharmacological interventions. These include adequate education of patients and carers, assurance of understanding by patients and carers and competent discharge planning, with good communication between hospital, general practitioners (GPs) and others involved in the patient’s care. Basically, the management remains under the care of the GP. However, consultation is highly beneficial, either through a hospital clinic, a cardiologist with appropriate experience in the management of CHF, or a general physician with similar experience and training in the management of CHF. The place of telemetry and telemedicine remains uncertain. These non-pharmacological approaches are described in Chapter 7.

In all of the above, co-ordination is critically important and hence the employment of a nurse co-ordinator is highly desirable to ensure adequate performance of all of the above. With additional training, it is possible that multi-disciplinary programme co-ordination and the current traditional roles of health professionals could be undertaken by other healthcare professionals, such as practice nurses, community matrons, and healthcare assistants. The roles of various health professionals are discussed below.

5.2 Hospital presentation

Patients presenting to hospital with CHF are most commonly significantly short of breath, because of acute pulmonary oedema. Acute pulmonary oedema is usually due to fluid overload: it presents with pulmonary rales and sometimes with wheezing. Other evidence of fluid retention is usually present (oedema, raised venous pressure, abdominal distension).

Transport to hospital is usually by ambulance, although some patients are brought by car or even by public transport. Urgent care may have been started beforehand by GP or ambulance personnel.
5.3 Emergency department

Emergency department care is directed toward resuscitation measures including:
- intranasal oxygen
- intravenous line insertion
- intravenous diuretic administration (usually furosemide)
- other medication, as required
- opioids and nitrates for patients with acute pulmonary oedema
- continuous positive airways pressure for some patients

Electrocardiographic monitoring is instituted and venipuncture may be undertaken for blood chemistry measurements. The diagnosis is confirmed, based upon history, including discussion with carer, physical findings and investigations.

5.4 Ward admission

On transfer to the ward, management of the above is continued:
- monitoring is continued
- fluid balance is established
- diagnosis is confirmed
- the cause of HF is defined

The underlying cause of HF is most likely to be coronary artery disease with past myocardial infarction or long-standing hypertension. The precipitating cause is also defined: this is commonly related to lapses in adherence to medication or behavioural advice. The principal aim of management is to achieve an appropriate euvolaemic state with control of fluid balance. This is achieved with a therapeutic regimen based upon diuretic, ACE inhibitor (or angiotensin receptor blocker) often with digoxin and possibly other drugs and consideration of warfarin, particularly for patients with atrial fibrillation. The patient is mobilised, usually within a day or two. Patient education is commenced. Family education is best coupled with patient education. The patient is prepared for future management which is documented in a discharge plan.

5.5 Discharge plan

The discharge plan involves communication with the GP and the making of an appointment for the patient to be seen by the GP. Appointments are also made for a review by a cardiologist, or physician/nurse, either at a hospital outpatient clinic or independent of the hospital, but preferably by a cardiologist or physician/nurse who has participated in the patient’s management. The patient is given a hand-held record for transfer of information between medical practitioners and others. Materials (fact sheets or booklets) are provided to support the advice given and arrangements are made for continued care. An assessment should be made of environmental and social factors that may affect the patient’s recovery after discharge. Services which the patient uses or may require need to be discussed, particularly if it appears that the spouse or principal carer may have difficulty in adequately supporting the patient.

5.6 Home arrangements

Home arrangements include assurance that the patient can and does keep appointments. If this does not occur, then reasons need to be explored and further appointments made by telephone. A home visit is made to ensure that regimens are understood, achievable and adhered to. Arrangements are made for regular reviews by a GP and a specialist.

An exercise programme is recommended for each patient and tailored to individual needs.
Such programmes mostly consist of simple activities of daily living at home and exercises directed toward improving the patient’s capacity to undertake those activities. Patients may attend a programme designed for cardiac patients following acute myocardial infarction or coronary bypass surgery, with exercises appropriately modified to suit the HF patient. However, referral to a specific HF exercise programme is preferable, if one is available.

Self care, often supported by the carer, is reviewed including dietary regimens, reduction of salt intake and careful control of fluid intake. Additional advice regarding modification of diuretic regimens depending on weight can be instituted. Long-term follow-up, either by telephone or by a home visit, is undertaken to assure adherence to regimens of care and self care, and to identify those patients and carers requiring further assistance. Patients and carers are advised about what to do if deterioration occurs through increasing shortness of breath or fatigue and what to do in emergencies.

5.7 Programme (nurse) co-ordinator

The above are best achieved with proper co-ordination of delivery of programmes. All successful multi-disciplinary programmes reported in the literature have involved the participation of a nurse co-ordinator. That co-ordinator is linked to the hospital from which patients have been discharged or to which they will be referred. Health care professionals consulted in fieldwork for this report agreed that many difficulties could be overcome with improved co-ordination of services and the availability of a designated case manager for CHF patients. Failure of referrals in hospital were partly attributable to frequent changes in staff, particularly junior doctors, who were often not aware of the existing arrangements. Feedback from practitioners also highlighted the fact that referral of CHF patients to other health professionals in hospital and after discharge frequently did not occur, both because of poor communication and a lack of allied health staff.

5.8 The role of the GP

The GP is the key person in the management of patients with CHF. The GP may have made the diagnosis in the first place and is likely to know the cardiological background of the patient and the family and social circumstances of the patient. The GP gives behavioural advice, prescribes medication, enquires into its effects and modifies treatment, as required. The GP recommends transfer to hospital / community HF service when necessary. It is to the GP that the patient returns for continued management after discharge from hospital for continued management. The continuum of care is therefore closely linked to the GP. The quality of the care is linked to the training of the GP and acceptance by the GP that referral is required to a hospital clinic or community heart failure service for specialist additional advice regarding best management of individual patients. A good relationship between the programme co-ordinator and GP is also helpful.

5.9 The role of the heart failure specialist nurse

The heart failure specialist nurse role has evolved as a result of a number of landmark studies that showed that specialised and intensive follow up of CHF patients, who are often elderly and vulnerable, improved outcomes and reduced hospitalisation. The heart failure specialist nurse role is critical in pre-discharge education, home visits after discharge, ensuring adherence to treatment, particularly up-titrating and monitoring drugs as well as early detection and treatment of clinical decompensation.
6. Pharmacological management of CHF

The key principles of the management of CHF involve appropriate pharmacological interventions. Such interventions have now been demonstrated to improve symptoms, functional capacity and quality of life significantly, coupled with reduction in hospital costs and prolongation of patient lives. The benefits of pharmacological intervention and maintenance treatments for patients with CHF have been reported in clinical practice guidelines in the United States of America and Europe and many other review papers.

The advances are clearly demonstrated in large, well funded, prospective randomised double blind clinical trials and are well reviewed in each of the above guidelines. In summary, very large, multi-centred trials have demonstrated benefits from angiotensin converting enzyme inhibitors (ACE inhibitors) and the addition of beta blockers. The place of diuretics, aldosterone antagonists, digoxin, and angiotensin receptor blockers (ARB) treatments are also reasonably well defined.

6.1 Diuretics

No randomised trials of diuretic use in CHF have been undertaken. However, it is clearly recognised that withdrawal of a diuretic regimen in those with moderate or severe CHF leads to fluid retention, marked increase in breathlessness and potential death. The recent ALLHAT study (of over 33,000 randomised patients with systemic hypertension) showed that treatment with a diuretic had benefits greater than treatment with ACE inhibitor or with calcium channel blocker, particularly in the delay of onset of CHF.

6.2 Angiotensin converting enzyme (ACE) inhibitors

ACE inhibitors have become standard recommended medication for all patients with CHF. By inhibiting the conversion of angiotensin I to angiotensin II, they reduce the effect of angiotensin II on arterioles. Hence they are powerful vasodilators and effective hypotensive agents which reduce the work of the left ventricle and reduce the progress of adverse left ventricular remodelling. Many randomised clinical trials of these drugs (captopril, enalapril, fosinopril, lisinopril, perindopril, quinapril, ramipril) have demonstrated their efficacy compared with placebo in improving life expectancy, functional capacity, functional class and quality of life. In some patients, adverse effects occur. These include hypotension, renal dysfunction, hyperkalaemia and cough.

6.3 Angiotensin receptor blockers (ARB)

In those patients who cannot take an ACE inhibitor, the substitute use of ARB is recommended. While these drugs (candesartan, eprosartan, irbesartan, telmisartan, losartan) have been demonstrated to be effective hypotensive agents, their role in CHF remains uncertain. Their efficacy is presumed rather than securely established. (only candesartan and valsartan (post-MI) are licenced for use in the treatment of heart failure).

6.4 Vasodilator drugs and nitrates

The combination of a vasodilatation regimen, using hydralazine and long acting nitrates (usually isosorbide dinitrate), is another possible alternative for use amongst those patients with CHF who are unable to take an ACE inhibitor.
6.5 Digoxin

The recent DIG study\textsuperscript{26} showed that amongst those patients with CHF receiving standardised other treatments, the group who were randomly allocated to receive digoxin died (or survived) at exactly the same rate as those allocated to placebo. Important, however, was the marked difference in the manner of death, and to some degree, the quality of life between the two groups. Those who received digoxin tended to die suddenly at home. Those taking placebo tended to die with progressive CHF in hospital. Further, those taking digoxin had somewhat better functional capacity and better quality of life. Thus, the place of digoxin in the management of CHF is currently established and recommended for all or almost all patients. The possibility that fewer sudden deaths may occur with use of digoxin if higher levels of serum potassium are maintained still merits investigation.

6.6 Spironolactone

The suppression of the effects of aldosterone by treatment with an ACE inhibitor was initially assumed. However, it later emerged that escape from suppression occurred and that the metabolic and fluid retaining effects re-emerged after continued medication with an ACE inhibitor. The aldosterone antagonist (spironolactone) was resurrected as a treatment, additional to the ACE inhibitor regimen. It was found that the addition of spironolactone was effective compared with placebo in a randomised double blind clinical trial\textsuperscript{27}. Hence, small doses of spironolactone are now recommended for patients with CHF, particularly those who have a lowered serum potassium level and a tendency to continued fluid retention. The potential hazard is the risk of hyperkalaemia, particularly amongst those with renal failure and especially those with diabetes.

6.7 Beta adreno-receptor blocking agents

Beta blocker treatment of CHF was initially introduced because it was recognised that the tachycardia coupled with CHF (driven by catecholamine stimulation) was often excessive. Hence, it was thought that treatment with a beta blocker could lead to more efficient cardiac function, with production of slower heart rate and consequent improved stroke volume, despite the otherwise cardio-inhibitory effects of beta blockade. Trials have demonstrated more favourable outcomes in patients in NYHA functional class II and III who received metoprolol\textsuperscript{28}, carvedilol\textsuperscript{29, 30} or bisoprolol\textsuperscript{31} than amongst those who received placebo, additional to otherwise best treatment with an ACE inhibitor and diuretic.

6.8 Levels of evidence for the effectiveness of treatments

Levels of evidence for the effectiveness of treatments, following MRC ratings, are set out in Table 7. Further details of MRC ratings appear in Appendix B.
Table 7. Levels of evidence for effectiveness of treatments (summarised)

- **I** Randomised controlled trials (RCTs), consistent, from different sources
- **II** At least one RCT without conflicting evidence (or a favourable balance of RCTs)
- **III** Observational and controlled studies, consistent and repeated from different sources
- **IV** Case series
- **EO** Expert opinion

**6.9 Levels of evidence for effectiveness of drug treatments**

Levels of evidence for drug treatment of patients with CHF are summarised in Table 8.

Table 8. Levels of evidence for pharmacological management of CHF

<table>
<thead>
<tr>
<th>Medication</th>
<th>Survival</th>
<th>Hospital readmission</th>
<th>Functional capacity</th>
<th>Quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diuretic</td>
<td>IV/EO</td>
<td>IV/EO</td>
<td>IV/EO</td>
<td>IV/EO</td>
</tr>
<tr>
<td>ACE inhibitor</td>
<td>I</td>
<td>I</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>Beta blocker</td>
<td>I</td>
<td>I</td>
<td>I</td>
<td>-</td>
</tr>
<tr>
<td>Angiotensin 2 Antagonist</td>
<td>II</td>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
<tr>
<td>Aldactone</td>
<td>II</td>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
<tr>
<td>Digoxin</td>
<td>-</td>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
<tr>
<td>Vasodilators</td>
<td>II</td>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
</tbody>
</table>

EO = expert opinion

While, in general, each outcome measure runs equally across the table for each type of drug, there are two exceptions. Quality of life on beta blocker may be improved in many patients because of functional improvement, while in others the blunting side effects of the beta blocker interfere with quality of life. In the case of digoxin, the drug favorably affects hospital readmissions, functional capacity and quality of life through reducing recurrence of episodes of CHF which may also lead to death.

However, treatment with digoxin is associated with occurrence of sudden death, usually at home. Hence, there is no overall mortality difference. On balance taking digoxin is likely to be preferred by most patients as their levels of function are better through the last few months or years of life.
6.10 Dosages

In major placebo controlled prospective clinical trials of pharmacological agents, there is an established target dosage, pre-set before the trial, often with a run in schedule of increasing dosage up to the target dose. Hence levels of evidence of effectiveness apply to a given dosage of a particular drug, not to a lesser dose (which may be ineffective) or to a higher dose (which may induce serious adverse effects).

The opinion is widely expressed in guidelines that dosages of drugs used should be equivalent to the dosage used in clinical trials. It has been found that such dosages can be achieved in up to 90% of patients treated with an ACE inhibitor and greater than 50% in patients treated with a beta blocker.

6.11 Adherence

A major problem in practice is the insecurity regarding patient adherence to prescribed medication or dosage of that medication. Hence, although appropriate medication is demonstrated to achieve the anticipated outcomes, this is often not the case in practice. Advice and support are required for many patients to ensure adherence to medication so that the desired benefits of drug treatment can be achieved.

With respect to the treatment of symptomatic CHF, the guidelines of the Lewisham PCT present recommendations for pharmacological management which are summarised in Appendix C.

6.12 Upward dosage titration

It is recognised that upward dosage titration is required in the introduction of ACE inhibitor medication. The aim is to avoid hypertension, renal failure or other adverse effects which can occur in some patients if the drug is introduced rapidly. It is usual to start with a small dose, possibly a quarter or less, of the target dose of the drug and then increase the dose over a few days while the patient is in hospital up to the target dose. Once that is achieved, it is then desirable to introduce a beta blocker in a minimal dose and gradually increase the dose of that up to the target dose used in clinical trials. This usually extends into the convalescent period after the patient has been discharged from hospital, although as a rule, it started while the patient is in hospital, once some stability has been achieved.

6.13 Combination therapy

The combination of drugs used for treatment of CHF is most likely to be more effective than the use of single drugs. Thus, beta blockers and spironolactone may be added to a diuretic and ACE inhibitor to achieve maximal effect. However, adverse effects may also occur. These adverse effects include renal failure, hyperkalaemia, hypovolaemia, postural hypotension and in the case of some drugs (eg some calcium channel blockers and at times beta blockers), worsening of CHF.
### 6.14 Recommendations: pharmacological management of CHF

#### Table 9. Recommendations: pharmacological management of CHF

<table>
<thead>
<tr>
<th>Level of evidence</th>
<th>Recommendation</th>
</tr>
</thead>
</table>
| EO/IV             | All patients with CHF who have symptomatic or other evidence of congestion should receive diuretic treatment  
                     - with loop diuretic if an acute episode  
                     - with loop or thiazide diuretic if not an acute episode |
| I                 | All patients with CHF should receive treatment with an ACE inhibitor unless contraindicated         |
| II                | All patients unable to take ACE inhibitor should be considered for treatment with ARB               |
| I                 | All patients treated with ACE inhibitor or ARB should be also treated with a beta-blocker unless contraindicated |
| II                | Symptomatic patients with CHF should be treated with digoxin unless contraindicated                 |
| II                | All patients with severe CHF, despite appropriate dosage of ACE inhibitor and diuretic, should receive spironolactone |
| EO                | All patients with CHF should have additional medication to control the causes of CHF (e.g. lipid-lowering agents, aspirin, hypotensive agents as indicated) |
| EO                | At time of institution of treatment with ACE inhibitor, renal function should be assessed           |
| EO                | Dosage of selective ACE inhibitor should start low and be titrated upwards to the dosage used in clinical trials, if possible |
| EO                | Dosage of selected beta-blocker should start low and be titrated upwards to dosage used in clinical trials, if possible |
| EO                | All patients with CHF should have standing blood pressure recorded, additional to lying or sitting   |
| EO                | All patients with CHF and AF should be considered for treatment with aspirin or warfarin             |

### 6.15 Suggested Indicators: pharmacological management of CHF

#### Table 10. Suggested Indicators: pharmacological management of CHF

- Proportion of patients taking:  
  - loop diuretic (e.g., furosemide)  
  - thiazide or other diuretic  
- Proportion of patients taking ACE inhibitor  
- Proportion of patients taking:  
  - Angiotensin 2 antagonist (ARB)  
  - vasodilator treatment  
- Proportion of patients taking beta-blocker  
- Proportion of patients taking digoxin  
- Proportion of patients taking spironolactone  
- Proportion of patients taking medication where indicated:  
  - to control underlying causes of CHF  
  - to address defined co-morbidities aggravating CHF  
- Proportion of patients whose renal function has been checked  
- Proportion of patients taking target dose (clinical trials dosage schedule) of ACE inhibitor  
- Proportion of patients taking target dose (clinical trials dosage schedule) of beta blocker  
- Proportion of patients whose standing blood pressure is recorded  
- Proportion of patients with CHF and AF taking aspirin or warfarin
### 6.16 Summary of key findings

The epidemiological estimates indicate that there are about 3,800 people with CHF in Lewisham, over half of whom are aged over 65 years. However, the recorded prevalence of patients identified with chronic heart failure based on the disease registers held in primary care identified in the Quality and Outcomes Framework is around 5/1000 population which equates to about 1,250 patients. This is lower than the expected prevalence of 15.3/1000 population which may indicate significant under-diagnosis of heart failure in primary care.

The number of newly diagnosed cases of heart failure expected in Lewisham is about 216 per year in those aged over 25 years (Table 1). Although admission rates are not a measure of true incidence of disease, it can be used as a proxy for incidence rates as the majority of patients are first diagnosed with heart failure following an emergency admission. The mean number of patients admitted with CHF per year is 262 (Table 3), and while mortality rates are surprisingly low, admissions rates are high, in comparison to other primary care trusts.

A needs assessment indicated that there was a need for a CHF service but no one particular model was identified as ideal by the stakeholders. There were also varying opinions as to where the service should be sited with a distinct dichotomy of views between the GPs who expressed a preference for a community service and hospital consultants, who preferred the service to be located within secondary care. The main issues identified were the need for specialist nurses, Cardiologists with an interest in heart failure, timely access to diagnostic tests, inadequate communication and discharge arrangements and palliative care.
7. Non-pharmacological management of CHF

7.1 Chronic disease management (CDM) programmes

The non-pharmacological management of patients is currently addressed in the framework of Chronic Disease Management (CDM). Sections 7.1 to 7.5 provide an overview of the evidence for the effectiveness of CDM programmes, which have been shown to have multiple benefits to patients, with levels of evidence for effectiveness set out in Table 11.

7.2 Levels of evidence for effectiveness of CDM for CHF

Table 11. Levels of evidence for effectiveness of CDM for CHF

<table>
<thead>
<tr>
<th>Program Ingredients</th>
<th>Survival</th>
<th>Hospital Admission</th>
<th>Functional Capacity</th>
<th>Quality of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive</td>
<td>II</td>
<td>I</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>Patient Education</td>
<td>III</td>
<td>III</td>
<td>III</td>
<td>III</td>
</tr>
<tr>
<td>Telephone follow-up</td>
<td>-</td>
<td>III</td>
<td>III</td>
<td>III</td>
</tr>
<tr>
<td>Home Visit</td>
<td>II</td>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
<tr>
<td>Exercise Program</td>
<td>II</td>
<td>II</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>Special Clinic</td>
<td>II</td>
<td>I</td>
<td>I</td>
<td>I</td>
</tr>
</tbody>
</table>

7.3 Cost

Cost saving, cost benefit and cost effectiveness are claimed by some to arise from their CDM programme for CHF. Theoretically, such cost saving and effectiveness should accrue. However, the implementation of a comprehensive programme, if it includes a special management clinic, may lead to costs which counter the savings that arise from reduced hospital readmissions. Not considered in any costing is the reality that living longer has its own delayed costs. Savings over 12 months may then be followed by added costs in the next year or years. The question of costing and discounting future costs needs to be further addressed.

7.4 Evidence for the effectiveness of CDM

Fifteen randomised controlled trials (Table 12) were identified for this review. In these studies, a total of almost 2,000 patients were randomised. The average age of patients was approximately 70-75 years. The most common period of follow-up to outcome measure was six months.

The outcome measures included symptoms or functional status (NYHA functional class or other measure of symptoms and function), reduction of readmissions to hospital, improvement in quality of life and cost saving within the period up to follow-up. Three studies reported improvement in symptoms or functional class while the remaining twelve did not specifically report on symptoms or functional class as an outcome.

Hospital readmissions were reduced in 13 of the studies in which this outcome was included. In one, there was no reduction in admission rate and in one it was not reported.

Improved quality of life was reported in all five studies where it was an outcome measure.
Cost savings were considered significant in five out of the six studies where this was investigated. In one study, there was no cost saving because the cost of the programme nullified the cost savings achieved through hospital admissions. In the remaining five studies, cost savings was not an outcome measure.

The possible benefit from CDM programmes on mortality reduction did not reach statistical significance in the trials, with up to one year follow-up, although a trend was apparent. Early meta-analysis of trials by McAlister et al\(^48\) confirmed the trend, but 95% confidence intervals were not convincing.

The concept that specialised and intensive follow up of these often elderly and vulnerable patients, aimed at correcting the aforementioned deficiencies in care, might improve outcome and reduce hospitalisation has been tested in two important studies. The first landmark study in this area was by Rich et al.\(^32\) These authors conducted a prospective, randomised trial of the effect of a nurse directed, multidisciplinary intervention on the rates of hospital readmission, quality of life, and costs of care within 90 days of discharge among elderly, high risk patients who were hospitalised for CHF. The intervention consisted of comprehensive education of the patient and family, a prescribed diet, social service consultation and planning for an early discharge, a review of medications, and intensive home and clinic based follow up with frequent telephone contact. Survival for 90 days without readmission was achieved in 64% of patients in the intervention group compared to 54% in the control group. The number of readmissions for CHF was reduced by 56% in the treatment group. Quality of life was significantly better in the intervention group and the overall cost of care was $460 less per patient in this group.\(^32\)

Stewart et al, as part of a larger clinical trial,\(^38, 39\) randomised hospitalised CHF patients with impaired left ventricular systolic function, exercise intolerance, and a history of at least one admission for acute heart failure to usual care or a home based intervention.\(^38, 39\) The 297 patients in the two randomised trials conducted by Stewart et al\(^38, 39, 43\) were followed up for three to six years\(^49\). The report demonstrated a significant difference in cumulative mortality over time. These benefits may not be attributable only to the single home visit undertaken soon after discharge. The home visit necessitated more formal discharge planning in hospital, opening up an additional avenue for communication and help throughout the trial and follow-up period and further facilitated access to a hospital cardiology clinic. Nevertheless, the outcome remains most impressive. It underlines the overall benefits of education, discharge plan, home visit, open avenues of communication and availability of a specialist clinic with good co-ordination by trained cardiac nurses.

In summary, there is persuasive evidence from these randomised controlled trials, that an CDM programme (almost irrespective of its nature) results in significant improvement in symptoms, markedly reduces readmissions to hospital (at least for 6 or 12 months) and leads to significant improvement in quality of life. Cost savings over the time of the intervention are also significant.
### 7.5 CHF management: prospective randomised controlled trials

#### Table 12. CHF management: prospective randomised controlled trials

<table>
<thead>
<tr>
<th>Authors</th>
<th>Number of patients</th>
<th>Average age</th>
<th>Follow-up (months)</th>
<th>Symptoms, function</th>
<th>Reduction of re-admissions</th>
<th>Improved quality of life</th>
<th>Cost saving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rich et al 1993</td>
<td>98</td>
<td>79</td>
<td>3</td>
<td>nr</td>
<td>27%</td>
<td>nr</td>
<td>nr</td>
</tr>
<tr>
<td>Schneider et al 1993</td>
<td>54</td>
<td>nr</td>
<td>1</td>
<td>nr</td>
<td>73%</td>
<td>nr</td>
<td>nr</td>
</tr>
<tr>
<td>Kostis et al 1994</td>
<td>20</td>
<td>66</td>
<td>3</td>
<td>yes</td>
<td>nr</td>
<td>yes</td>
<td>nr</td>
</tr>
<tr>
<td>Rich et al 1995</td>
<td>282</td>
<td>79</td>
<td>3</td>
<td>nr</td>
<td>44%</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>Cline et al 1998</td>
<td>190</td>
<td>75</td>
<td>12</td>
<td>nr</td>
<td>35%</td>
<td>nr</td>
<td>yes</td>
</tr>
<tr>
<td>Serxner et al 1998</td>
<td>109</td>
<td>71</td>
<td>6</td>
<td>nr</td>
<td>52%</td>
<td>nr</td>
<td>yes</td>
</tr>
<tr>
<td>Stewart et al 1998,1999</td>
<td>97</td>
<td>75</td>
<td>18</td>
<td>nr</td>
<td>42%</td>
<td>nr</td>
<td>yes</td>
</tr>
<tr>
<td>Ekman et al 1998</td>
<td>158</td>
<td>80</td>
<td>6</td>
<td>nr</td>
<td>-5%</td>
<td>nr</td>
<td>nr</td>
</tr>
<tr>
<td>Jaarsma et al 1999</td>
<td>179</td>
<td>73</td>
<td>9</td>
<td>nr</td>
<td>49%</td>
<td>nr</td>
<td>nr</td>
</tr>
<tr>
<td>Gattis et al 1999</td>
<td>181</td>
<td>55-77</td>
<td>6</td>
<td>yes</td>
<td>yes</td>
<td>nr</td>
<td>nr</td>
</tr>
<tr>
<td>Stewart et al 1999</td>
<td>200</td>
<td>75.5</td>
<td>6</td>
<td>nr</td>
<td>42%</td>
<td>yes</td>
<td>nr</td>
</tr>
<tr>
<td>Blue et al 2001</td>
<td>165</td>
<td>75</td>
<td>12</td>
<td>nr</td>
<td>62%</td>
<td>yes</td>
<td>nil</td>
</tr>
<tr>
<td>Kasper et al 2002</td>
<td>200</td>
<td>65</td>
<td>6</td>
<td>yes</td>
<td>41%</td>
<td>yes</td>
<td>nil</td>
</tr>
<tr>
<td>Doughty et al 2002</td>
<td>197</td>
<td>73</td>
<td>12</td>
<td>nr</td>
<td>41%</td>
<td>yes</td>
<td>nr</td>
</tr>
<tr>
<td>Krumholtz et al 2002</td>
<td>88</td>
<td>73</td>
<td>12</td>
<td>nr</td>
<td>39%</td>
<td>yes</td>
<td>yes</td>
</tr>
</tbody>
</table>
7.6  Comprehensive CDM programme – programme description

CDM programmes usually involve a nurse co-ordinator/case manager working with the patient, family, general practitioner, physician or cardiologist and other health professionals. A CMD programme for CHF is recommended for effective:

- in-patient education
- assessment and risk screening
- discharge planning
- communication between hospital, community, patients and carer, and health professionals

Risk screening in hospital will help to identify patients and carers who are likely to need additional help following the patient’s discharge from hospital, especially an early home visit or social services assistance.

A chronic disease management programme also needs to include:

- early telephone follow-up and continued telephone availability
- home visit for those identified to be most in need
- home based walking and exercise programme
- group physical, social and supportive activities through community health centres or elsewhere
- long-term follow-up and support for patient and carer through community health centres or other organisations
- multi-disciplinary case management plans, with team meetings

Programmes including most or more than one of the ingredients of CDM listed above are clearly effective in each of the four outcome measures based upon evidence from multiple randomised clinical trials, and confirmed by observational studies. These outcome measures are survival, hospital readmission, functional capacity and quality of life.

7.7  Patient education

The benefits of patient education programmes alone (in-patient education) are relatively weak in affecting the outcomes listed, although they may lead to improved patient knowledge, at least in the short term. Some programmes have shown further benefits, while others have shown no statistically significant benefits. Patient and carer education should include general counselling, including:

- inpatient education (if an inpatient)
- physician advice and nurse co-ordinator explanation (if not an inpatient)

Specific education and instruction is needed regarding the following:

- Medication, purposes, side effects (eg, problems related to diuretic treatment)
- Recognition of need for medication and continued adherence to the prescribed medication
- Recognition of fluid retention related to weight gain (eg, two kilograms over two days)\(^{50}\)
- Awareness of weight loss, which may indicate other problems and increase the risk of falls
• Encouragement of patients/families to enquire about any recognised changes or any recognised concern
• Explanation and understanding of the need for fluid restriction and salt restriction
• Understanding of the effects of tobacco and alcohol
• Need for control of weight, diabetes, blood pressure and cholesterol
• Understanding of mood disturbance and behavioural or personality change
• Maintenance of activity and exercise
• Patient education should be conducted, when possible, together with the carer or other family member

There was agreement among feedback group participants that patients generally had a poor understanding of their condition and their regimens, especially their medication. It is therefore recommended that patients should be encouraged to question their GPs about the purpose of their medication and whether it was necessary to continue the medication. Patients need to be empowered to ask their GP about their long-term management, rather than receiving advice relating only to the first few weeks following hospital discharge.

According to feedback from practitioners, patients also need further education about diet, especially salt restriction and fluid restriction. Some patients may benefit from referral to a service such as Quitline if they continue to smoke. Patients also need to have a better understanding of their prognosis and the things which they should look for, to identify whether their CHF was well controlled or not.

### 7.8 Home visit

A home visit by a specialist nurse has been shown in one study to be as effective as a comprehensive programme. However, patients in this trial who were randomised in hospital to receive the intervention, needed preparation and understanding of the reasons for the visit. Thus, those in the intervention group received information in hospital and a more comprehensive discharge plan, in addition to the post-discharge home visit. Home visits, however, do appear to be the most powerful single ingredient of comprehensive programmes. Further, home visits offer an additional communication line during follow-up. The comprehensive approach, pioneered by Rich, was largely based on home visits by nurses and was clearly beneficial in all outcome measures.

### 7.9 Telephone follow-up

Telephone follow-up alone appears to have limited benefits. It is, however, useful for enquiry and support and can help to identify patients who particularly need an early home visit. The place of telemedicine for CHF patients remains uncertain. According to practitioners who participated in the focus groups, a particular gap in current management is the failure to provide patients with access to help in emergencies, particularly at night. In practice, few services are available after hours. Further, patients and carers also need the name of a particular contact person and a designated phone number for follow-up, should help be required.
7.10 Exercise programme

Evidence from multiple randomised clinical trials (section 7.19) demonstrates that the same or similar benefits are produced by attending an ongoing supervised exercise programme as are obtained from a CDM programme. Unfortunately, access to exercise programmes is very low, with less than 20% of CHF patients enlisted on exercise programmes. Low attendances were attributed to limited access to cardiac rehabilitation programmes, a lack of awareness of the existence of such services by GPs, patients, and others, and of their demonstrated benefits. Practitioners emphasised that it is essential for GPs and other health care providers to reinforce the importance of attending available programmes and to motivate patients to attend. Home based programmes are also necessary for those who may not be able or willing to attend group programmes, particularly older patients, those with limited access to community programmes, and patients from culturally and linguistically diverse backgrounds.

7.11 Designated CHF clinic

A designated CHF clinic is an effective means of centralising a chronic management programme and providing patients with expert advice and management. These benefits have been demonstrated in randomised clinical trials and were endorsed by practitioners involved in the focus groups. They considered both specific heart failure clinics and chronic disease management units to be valuable.

7.12 Medical management

Observational studies have demonstrated that management by experts in the field (eg cardiologist) is likely to reflect closer adherence to practice guidelines than management by general physicians or family physicians. It has also been noted that those patients whose management is shared between GP and specialist cardiologist have better outcomes than those managed by GP alone. While these better outcomes may partly be related to patterns of prescribing particular doses of drugs, there may also be greater targeting of advice regarding behaviours and their importance.

The guidelines produced in the United States of America review and endorse six papers, which demonstrate the need for expert cardiologist input into all phases of management of patients with CHF. These reports are of observational studies undertaken in different health care systems. Further, the reports are written by cardiologists. Generally cardiologists see patients who present with a single major cardiac condition, often to a coronary care unit. Such patients are less likely to have multiple co-morbidities. They commonly have a clearer diagnosis and defined management pattern than those patients seen by geriatricians and general physicians. Thus, while cardiologists may appear to manage CHF in a manner closer to the propagated guidelines, they may not be adequately experienced in the management of patients presenting in older age with highly complicated problems and multiple co-morbidities.
7.13 Comments

In summary, a CDM programme for all patients with CHF should aim to ensure availability of a comprehensive multi-disciplinary approach to the care of each patient. Each patient is likely to have needs in common with others but will also have individual needs.

The CDM programme should be co-ordinated by a nurse co-ordinator.

It would seem most appropriate that the direction of the CDM programme should be co-ordinated, at least initially, from the hospital from which patients have been discharged or to which they would be likely to be readmitted or admitted.

The core features of such a CDM plan should include:

- patient and carer education
- provision of literature with explanation
- hand-held record of diagnoses, medication, recommended behaviours, interventions, admissions
- discharge plan including written (verbally confirmed) appointments with:
  - GP
  - cardiologist/physician/specialist nurse /clinic
  - exercise group
  - community services
  - other services
- home visit shortly after hospital discharge preferably within one week that addresses:
  - medication review
  - review of health behaviours
  - checking of scales at home (or elsewhere)
  - activity review
  - review of psychosocial functioning
  - review of coping by carer and carer’s needs
- telephone contact for follow up of
  - missed appointments
  - emergency patient needs
  - weight and symptoms
  - physiotherapist, occupational therapist or other allied health needs
  - community health centre attendance and other group activities
  - GP attendance and reinforcement of importance of that attendance
  - whether planned services or assessment have actually been implemented

These approaches should be clearly understood and implemented by all who are involved in the patient’s management.
### 7.14 Recommendations: chronic disease management of CHF

#### Table 13. Recommendations: chronic disease management of CHF

<table>
<thead>
<tr>
<th>Level of evidence (reduction of acute HF)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Personal education of patient and carer is delivered while in hospital</td>
<td>II</td>
</tr>
<tr>
<td>2 If not admitted to hospital, the same personal education is delivered to the patient and carer at home</td>
<td>EO</td>
</tr>
<tr>
<td>3 Education should be interactive with full participation of patient/carer, questions answered, and explanation and reasons given for each therapeutic</td>
<td>EO</td>
</tr>
<tr>
<td>4 Questions should be asked to ensure that patient and carer understand advice</td>
<td>EO</td>
</tr>
<tr>
<td>5 Formal discharge plan should be arranged with assurance of all appointments and procedures</td>
<td>II</td>
</tr>
<tr>
<td>6 Telephone call made to assess progress and identify need for further assistance</td>
<td>II</td>
</tr>
<tr>
<td>7 Early home visit should be made (preferably within one week of discharge), ideally to all patients but at least to those identified as needing further</td>
<td>II</td>
</tr>
<tr>
<td>8 Further education and reinforcement of advice should be given during home visit</td>
<td>II</td>
</tr>
<tr>
<td>9 Follow-up by telephone should be arranged for missed appointments</td>
<td>EO</td>
</tr>
<tr>
<td>10 All patients must have GP appointments confirmed</td>
<td>II</td>
</tr>
<tr>
<td>11 All patients should have referral to cardiologist or physician (individual or in clinic)</td>
<td>II</td>
</tr>
<tr>
<td>12 All patients should have a hand-held record of medical conditions and medication</td>
<td>II</td>
</tr>
</tbody>
</table>

#### Education

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>13 All patients should receive simple education material regarding their condition (booklets, pamphlets, fact sheets, videos, tapes)</td>
<td>EO</td>
</tr>
<tr>
<td>14 All patients should understand need for adherence to medication with consideration of dose and compliance aids</td>
<td>III</td>
</tr>
</tbody>
</table>
| 15 Patients should keep a diary to record  
– taking of medication  
– daily weight | EO |
| 16 All patients should understand the significance of weight gain (greater than 1.5kg in one day or 2kg in two days) | EO |
| 17 All patients should understand the risks of smoking and patients who smoke should be referred to smoking cessation programs | II |
| 18 All patients should be aware of risks of infection, particularly respiratory, and have annual influenza vaccinations and 3-5 yearly pneumococcal  
_ includes patients and carers_ | EO |

EO = expert opinion
7.15 Proposed indicators: chronic disease management of CHF

Table 14. Proposed indicators: chronic disease management of CHF

<table>
<thead>
<tr>
<th></th>
<th>Indicator</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Proportion of patients receiving education while in hospital</td>
</tr>
<tr>
<td>2</td>
<td>Proportion of patients receiving education at home</td>
</tr>
<tr>
<td>3-4</td>
<td>Proportion of patients asking appropriate questions &amp; responding to questions</td>
</tr>
<tr>
<td>5</td>
<td>Proportion of patients receiving formal documented discharge plan</td>
</tr>
<tr>
<td>6-8</td>
<td>Proportion of patients receiving telephone call, home visit and accepting further advice or asking further questions</td>
</tr>
<tr>
<td>9</td>
<td>Proportion of patients missing appointments and proportion being telephoned to establish cause and make new appointment</td>
</tr>
<tr>
<td>10</td>
<td>Proportion of patients who have GP appointment confirmed</td>
</tr>
<tr>
<td>11</td>
<td>Proportion of patients who attend cardiologist/physician or clinic by appointment</td>
</tr>
<tr>
<td>12</td>
<td>Proportion of patients accepting hand-held record</td>
</tr>
<tr>
<td>13</td>
<td>Proportion of patients accepting education materials</td>
</tr>
<tr>
<td>14</td>
<td>Proportion of patients with an established understanding of their medication &amp; the need for adherence</td>
</tr>
<tr>
<td>15</td>
<td>Proportion of patients keeping a diary of daily weight and medication</td>
</tr>
<tr>
<td>16</td>
<td>Proportion of patients understanding significance of weight gain</td>
</tr>
<tr>
<td>17</td>
<td>Proportion of patients with a history of smoking who are still smoking</td>
</tr>
<tr>
<td>18</td>
<td>Proportion of patients currently vaccinated for influenza and pneumococans</td>
</tr>
</tbody>
</table>

7.16 Staff and facilities

7.16.1 Programme (Nurse) co-ordinator

All integrated or multi-disciplinary programmes which have demonstrated significant benefit in patient well-being and have led to reduction of episodes of acute HF (which lead to hospital admissions) have been dependent upon a programme (nurse) co-ordinator, trained in the management and support of patients with CHF. Without such skilled nursing support, added to usual care (GPs, specialist and hospital emergency and inpatient management), programmes are ineffective. Clinical trials have demonstrated repeatedly that usual care alone is much inferior to CDM programmes.

7.16.2 Other health professionals

Personnel, additional to those involved in usual care and the nurse co-ordinator, may include pharmacist, social worker, psychologist, district nurses, community matrons, practice nurses, community health centre staff, cardiac rehabilitation nurses, physiotherapists, diéticians and others, as required.
### 7.17 Recommendations: staff and facilities for CDM of CHF patients

Table 15. Recommendations: staff and facilities for CDM of CHF patients

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>A programme (nurse) co-ordinator is required for effective CDM of CHF patients</td>
</tr>
<tr>
<td>2</td>
<td>Other health professionals and community care staff should be available, as required. Some may have special expertise appropriate to patients with specific difficulties (e.g., respite care worker, council support staff, community care services)</td>
</tr>
<tr>
<td>3</td>
<td>The nurse co-ordinator requires good access to cardiologists/physicians or clinics in the region and hospital support</td>
</tr>
<tr>
<td>4</td>
<td>The nurse co-ordinator needs to establish bi-directional supportive interactions with GPs in the region</td>
</tr>
<tr>
<td>5</td>
<td>Special training of potential nurse co-ordinators is required, through courses, to expand the accessibility of the knowledge base required for the specific nature of the work</td>
</tr>
<tr>
<td>6</td>
<td>Administrative and other supports are required, best sited in the hospital or community centre through which the CDM programme is delivered</td>
</tr>
</tbody>
</table>
7.18 **Continuum of care: possible evidence-based pathway**
The need for continuum of care is clear from the literature and accepted as best practice.

**Table 16. Continuum of Care**

<table>
<thead>
<tr>
<th>Time-base</th>
<th>Management</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inpatient*</td>
<td>Registration of patient&lt;br&gt;Medication&lt;br&gt;Mobilisation&lt;br&gt;Co-ordinator visit&lt;br&gt;Risk screen&lt;br&gt;Patient and carer education&lt;br&gt;Patient and carer understanding&lt;br&gt;Problem recognition&lt;br&gt;Family education</td>
</tr>
<tr>
<td>4-12 days</td>
<td>Referrals arranged&lt;br&gt;Appointments confirmed&lt;br&gt;Medication understanding checked&lt;br&gt;Education materials&lt;br&gt;Hand-held record&lt;br&gt;Communication with carers</td>
</tr>
<tr>
<td>Establishment of care pattern</td>
<td>Home visit to patient and carer&lt;br&gt;GP visit by patient&lt;br&gt;Telephone contact&lt;br&gt;Medication check&lt;br&gt;Weight/scales check&lt;br&gt;Education review&lt;br&gt;Understanding assessment&lt;br&gt;Activity/walking/exercise programme&lt;br&gt;Clinic/cardiologist/physician review</td>
</tr>
<tr>
<td>Discharge</td>
<td>Home visits to patient and carer&lt;br&gt;GP visits by patient&lt;br&gt;Clinic/cardiologist/physician review&lt;br&gt;Telephone contact&lt;br&gt;Medication/weight checks&lt;br&gt;Maintenance of understanding&lt;br&gt;Maintenance of activity programme&lt;br&gt;Family support&lt;br&gt;Community programmes</td>
</tr>
<tr>
<td>Preparation for Convalescence</td>
<td></td>
</tr>
<tr>
<td>Convalescence</td>
<td>&lt; 10 days&lt;br&gt;Setting of self-care management programmes, family, social and other supports</td>
</tr>
<tr>
<td>Continued care</td>
<td></td>
</tr>
<tr>
<td>Lifetime programme of self-care, prevention of lapses, recurrences and readmissions</td>
<td></td>
</tr>
</tbody>
</table>
7.19 Exercise training and rehabilitation

In reviewing the evidence of the effectiveness of exercise training in CDM of CHF, it is apparent that almost none of the randomised clinical trials of CDM includes a formal exercise programme. The evidence of benefits from exercise in patients with CHF comes from studies demonstrating improvement in functional capacity, well-being, life expectancy and reduced hospital readmissions from formal exercise training programmes, usually without any report of education or patient support. These programmes are similar to many physically oriented programmes of cardiac rehabilitation in USA and Europe. They are, however, very different from the cardiac rehabilitation programme pattern of exercise and education as in the United Kingdom. The evidence, however, is extended in some studies to show benefits from home exercise programmes and the suggestion that patients may be enrolled in a comprehensive programme from which there may be additional benefits.

Traditionally, exercise has been regarded as disadvantageous for patients with CHF. Rest was recommended and prolonged rest was recommended by some. This advice was reasonably well received by patients who noted that, with exertion, they became uncomfortable with breathlessness and fatigue. Patients naturally became progressively more inactive. It has also been shown that patients tend to relapse and return to a state of relative physical inactivity after attending an exercise programme, guided by their symptomatic disability. Physical inactivity leads to muscular wasting, muscular weakness and progressive impairment of functional capacity that can be corrected by aerobic exercise. Exercise training, involving both aerobic activity and strength training exercise, results in progressive improvement in functional capacity. The physiological basis for this is now well understood. It is not induced by changes in pulmonary or cardiac function, but in peripheral muscle efficiency. Peripheral muscles increase in size and cellular structural change has been demonstrated. More efficient oxygen extraction and utilisation has been demonstrated, so that venous blood leaving the muscles is more deoxygenated and contains more carbon dioxide. This is readily handled in the lungs. Thus, although some talk of cardio-pulmonary training or cardio-pulmonary conditioning, it should be recognised that such conditioning or training in patients with CHF has little or nothing to do with the heart and lungs (as indeed is the case in most middle-aged people enrolled in exercise training programmes. Prolonged endurance training is required to modify maximal cardiac output.)

There are now many studies which demonstrate the clear benefits of exercise training in patients with CHF. These have all been essentially physiologically monitored studies, observing improvements in functional capacity, measured by direct gas analysis, heart rate and secondarily by symptoms, functional capacity and quality of life. Suggested instruments to use to assess functional status and outcomes, including quality of life, are listed in Appendix E.

For patients with CHF, it remains problematic how best to deliver an activity/exercise programme. One concept is to use the cardiac rehabilitation (CR) model of group exercise and education. Some suggest that patients with CHF may be included among patients attending a group programme during convalescence following a cardiac event. One must be careful about adopting such a policy, however. One major reason for non-attendance of younger convalescing patients at a CR programme is that the group of patients includes a large number of older or more disabled patients than themselves. The inclusion of patients with CHF could markedly worsen the position for younger patients. While some practitioners thought it was appropriate to include CHF patients in a mainstream group exercise programme, others considered that CHF patients, particularly older CHF patients, might be better handled in a separate group. They pointed out that CHF patients need close monitoring and have different educational needs from other cardiac patients. They also have more disabling symptoms and slower rates of improvement. It is recommended that CHF patients could attend a programme with other cardiac patients, provided patients with CHF were separated from the others.
Nevertheless, the benefits should not be missed of the opportunity for appropriate CHF patients to take up group exercise together under the care of trained CHF specialists.

### 7.20 Recommendations: exercise and activity programme

#### Table 17. Recommendations: exercise and activity programme

<table>
<thead>
<tr>
<th>Level of evidence</th>
<th>Recommendations</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>1. A dynamic (aerobic) exercise programme, starting at low level and slowly increasing in duration, frequency and intensity of preferably daily activity should be devised for each patient</td>
</tr>
<tr>
<td>II</td>
<td>2. The level of activity should be supported by assessment of progress through verbal report, observation and formal measurement of walking capacity (eg 6 Minute WalkTest)</td>
</tr>
<tr>
<td>I</td>
<td>3. Strength training, with use of muscle groups against resistance (similar to many activities of daily living), should be incorporated into the exercise programme</td>
</tr>
<tr>
<td>III</td>
<td>4. Long term support, enquiry and supervision are required to assure adherence to home activity and exercise</td>
</tr>
<tr>
<td>I</td>
<td>5. Formal group exercise training programmes are recommended where there is a sizeable HF management programme</td>
</tr>
<tr>
<td>EO</td>
<td>6. Group exercise may be limited to patients with CHF or may be grafted on to a cardiac rehabilitation exercise programme</td>
</tr>
</tbody>
</table>

#### 7.21 Suggested indicators: exercise and activity programme

#### Table 18. Suggested indicators: exercise and activity programme

<table>
<thead>
<tr>
<th>Process</th>
<th>Outcome (eg at 3 months and at 12 months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Proportion of patients receiving inpatient education regarding benefits of activity</td>
<td>6. Patient activity</td>
</tr>
<tr>
<td>2. Proportion of patients with a written home activity and exercise programme</td>
<td>7. Functional class (eg NYHA functional class, Specific Activity Scale or 6 Minute Walk Test)</td>
</tr>
<tr>
<td>3. Proportion of patients participating in a home activity and exercise programme</td>
<td></td>
</tr>
<tr>
<td>4. Proportion of patients referred to group exercise (“rehabilitation”) programme</td>
<td></td>
</tr>
<tr>
<td>5. Proportion of patients attending a group exercise programme</td>
<td></td>
</tr>
</tbody>
</table>
8. Self care in CHF

The regimens of care for CHF patients are often complex and demanding. As such, they are commonly difficult for patients and carers to follow. To encourage adherence, patients and carers need education about these regimens, particularly those concerning medication. They also need to acquire skills for self-management. Self-management education and training, incorporating self-efficacy principles, can lead to many positive outcomes for people with chronic conditions. The Department of Health recently funded a number of projects under the Chronic Disease Management initiative to test self management service delivery models for patients with chronic conditions, including CHF.

The following areas of self management are particularly relevant for patients with CHF. Major medical problems may occur if simple errors are made in these regimens.

8.1 Weight

The need for patients to weigh themselves daily is often poorly understood by patients. Weight gain is commonly due to fluid retention, which precedes the appearance of symptomatic failure with pulmonary or systemic congestion. Hence patients need to understand the sequence and the hazards. A gain of greater than 1.5kg over 24 hours suggests developing fluid retention\(^1,23\) and an increase of greater than 2.0kg over two days does likewise\(^24\). This weight increase necessitates an increase in loop diuretic medication as a semi-urgent matter. Patients may be trained to respond by taking more diuretic with GP agreement. Alternatively, an urgent appointment is needed with the GP.

Making a daily record of weight can also stimulate the patient’s attention during the day towards daily activity levels and appropriate diet.

Weight loss by patients should be reported to the GP. Weight loss may occur because of a loss of appetite, induced by renal or hepatic failure, hepatic congestion, or it may be a marker of psychological depression. Weight loss may foreshadow significant postural hypotension and falls.

8.2 Fluid intake

Most guidelines have consensus views that fluid intake should be limited to 1.5 litres per day (or 2 litres in hot weather)\(^1\text{–}3\). Specific advice to drink only when thirsty may have similar benefits. Excess fluid intake may not be coupled with greater urinary output and hence may tip a patient into acute HF.

8.3 Diuretic variation

With loop diuretics (e.g., furosemide), the diuresis is considerable and lasts for just a few hours. Hence if the patient plans on being out during the day, the morning dose of the diuretic may not be taken. The patient may intend to take the diuretic in the evening but, not uncommonly, forgets. As a result, pulmonary oedema may occur during the night.

For patients with rapid diuresis, it is often better to take a thiazide diuretic in the morning and a half dose of furosemide in the evening, either on a regular or opportunistic basis. Alternatively, the furosemide dose may be divided into a morning and afternoon dose. Another problem with some patients is that they take their diuretic in the morning and their fluid intake in the evening. Thus, they may be dehydrated in the morning and volume overloaded in the night.
8.4 Medication adherence

Independently of the problems which may arise from diuretic management, other medication may be ceased. Some patients consider that a prescription represents a course of treatment which is terminated when the supplied medication runs out. Other patients note that they feel well and hence consider medication is no longer required. Some cease taking their medication because the drugs are too costly. It is common for patients to reduce the dosage of prescribed medication. With an ACE inhibitor or beta blocker, that can also lead to acute HF.

Carers of patients with impaired attention, memory or recall may take responsibility for medication usage to ensure adherence by the patient.

8.5 Nutrition

With episodes of acute HF, appetite is much reduced and weight loss may occur. With recovery from failure, recovery of appetite leads to regain of weight, usually slowly. However with perceived enforced inactivity, progressive weight gain may occur and contribute to occurrence of acute HF.

The demoralising effect of CHF and consequent disability commonly leads to psychological depression, with abandonment of dietary fat or other restriction to which the patient may have previously adhered. Combined increases in saturated fat intake and weight, and increasing insulin resistance and blood pressure, may lead to further episodes of myocardial infarction or ischaemia with severe adverse consequences.

Salt restriction, in the form of no added salt at the table and no added salt in cooking, plus avoidance of salty foods, tends to reduce fluid retention and decreases the incidence of congestion and worsening CHF.

8.6 Activity

Following awareness of symptoms, the natural tendency for patients is to do whatever seems reasonable to avoid those symptoms. Hence, recognition that effort induces undue dyspnoea leads to progressive physical inactivity. That may lead to further impairment of functional capacity due to muscular inefficiency and a worsening physical state. Patients need to understand that they would be better off being somewhat active rather than following the restrictive suggestion arising from breathlessness on effort.

8.7 Comments

Learning and retaining information, such as that outlined above, is a very considerable requirement imposed on patients, carers and health professionals. The individual patient’s response to such complex and demanding regimens may significantly influence outcomes, particularly inability to control CHF. Family members or carers may face difficulties in encouraging the patient to follow these regimens, or may be overprotective, potentially inducing adverse outcomes. It is therefore important to involve them in the patient’s education and to discuss any difficulties arising.
8.8 Recommendations: self care

Table 19. Recommendations: self care

Patient and carer education and understanding should embrace the following:

1. Daily record of weight. Response to weight gain greater than 1.5 kg in 24 hours or 2.0 kg in 48 hours. Response to weight loss
2. Limitation of fluid intake to 1.5 litres per day (2.0 litres per day in hot weather)
3. Establish pattern of best timing of diuretic medication and of drugs used, with GP agreement
4. Understanding of need for long term medication rather than course of treatment
5. Control of total caloric intake, persistence of saturated fat restriction
6. Salt restriction through no added salt at table nor in cooking, plus avoidance of highly salted foods
7. Persistence with activities (walking and activities of daily living) despite induction of dyspnoea, with attempts to be active to level of awareness of breathing (not breathlessness) at least half an hour per day
8. Dental: inform dental practitioners of diagnosis and current medication. In cases of CHF with mitral valve regurgitation, antibiotic therapy, if prescribed, should be taken
9. When in doubt about any aspect of management or behaviour, seek advice from professionals engaged in their care eg GP

8.9 Suggested indicators: self care

Table 20. Suggested indicators: self care

1. Proportion of patients recording daily weight
2. Proportion of patients who measure (directly or indirectly) daily fluid intake
3. Proportion of patients aware of possible variation in diuretic timing and dosage
4. Proportion of patients aware of need for and adherence to regular medication intake
5. Proportion of patients avoiding high calorie and high saturated fat foods
6. Proportion of patients not having salt in cooking and at table
7. Proportion of patients adhering to walking and other activity pattern
8. Proportion of patients seeking advice regarding any of the above
9. Palliative Care

9.1 Perceptions of illness

The perceptions of patients regarding their illness have been an important focus of research in recent years. This has arisen through the gradual recognition that delivery of all aspects of care in patients with advanced CHF has been poorly directed, poorly co-ordinated and poorly delivered. Problems confronting patients had not previously been adequately investigated. Conclusions arising from recent studies are outlined in this section.

Murray et al\textsuperscript{53} from Edinburgh undertook qualitative interviews with patients, carers and others concerned in advanced CHF and lung cancer. They concluded that patients with advanced CHF had a different illness trajectory, with uncertain outcomes and prognosis compared with the linear and predictable course of patients with lung cancer. They reported that patients with CHF had less information about and poorer understanding of the condition and were less involved in decision making. While the major issue confronting those with lung cancer was facing death; frustration, progressive losses, social isolation and the stress of balancing and monitoring a complex medication regimen dominated the lives of patients with cardiac failure. Further, they found that cardiac patients received less help, social and palliative care services and care was often poorly co-ordinated.

The authors present experiences of patients with CHF compared with those of patients with lung cancer:

- gradual decline punctuated by episodes of acute deterioration; sudden, usually unexpected death with no distinct terminal phase
- feel ill but told you are well
- little understanding of diagnosis and prognosis
- “I know it won’t get better but I hope it won’t get any worse”
- relatives isolated and exhausted
- daily grind of hopelessness
- much co-morbidity to cope with; heart often not seen as main issue
- shrinking social world dominates life, little contact with health and social services
- feel better on treatment: work of balancing and monitoring in the community
- less access to benefits with uncertain prognosis
- specialist services rarely available in the community
- less priority as a “chronic disease” and less priority later as uncertain if yet “terminally ill”

These problems are recognised by many health professionals and carers. This paper clearly sets out the deficiencies in management of those patients with advanced CHF, who are approaching or requiring palliative care. It addresses the profound problems of patients, carers and professionals in addressing illness trajectory, delivery of information and understanding of illness and prognosis, losses and uncertainties affecting living with the illness and the grave deficiencies of service provisions. Feedback group participants confirm the similarity in perceptions of people with CHF in Lewisham. The need for a more open approach to palliative care are highlighted in many papers and reports.\textsuperscript{54-68}
9.2 General palliative care

The National Institute for Clinical Excellence (NICE) guidelines published in 2004\textsuperscript{69,70} suggested the following as a definition of palliative care:

- Assessment of patient and carer need for support.
- Information to patients and carers known as signposting.
- Co-ordination in and out of hours and across boundaries.
- Basic levels of symptom control.
- Psychological, social, spiritual and practical support.
- Open and sensitive communication.
- Referral to specialist palliative care when necessary.

Managed frameworks of care include the Gold Standard Framework (GSF) \textsuperscript{71} and the Liverpool Care Pathway (LCP) \textsuperscript{72}. They were both developed as tools to organise and improve the care of people with advanced cancer, but are equally applicable for people with advanced non-malignant diseases such as heart failure.

Two or more of the following criteria may be used for placing a patient with heart failure on the ‘Supportive Care Register’ of the GSF:

- NYHA III or IV
- Patient is thought to be in the last year of life by the care team
- Patient has repeated hospital admissions with symptoms of heart failure
- Patient has difficult physical/psychological symptoms despite optimal tolerated therapy

Two or more of the following criteria may be used for placing a patient with heart failure on the LCP, when the multi-professional team agrees the patient is dying (this of course, is a clinical judgement):

- The patient is bedbound
- Semi-comatose
- Only able to take sips of fluid
- No longer able to take tablets

For patients with advanced heart failure not responding to maximum tolerated therapy and with deteriorating renal function, it may be appropriate for the multi-professional team to consider LCP. Similarly, it may also be appropriate to consider LCP for patients not wishing hospital care and deteriorating with an exacerbation of heart failure. Guidelines for referral and management of end stage heart failure are in Appendix F.

9.3 Specialist palliative care

Specialist palliative care services are provided by statutory and voluntary organisations in community, hospice and hospitals settings. The availability of such services varies considerably across different regions. The provision of hospice beds, palliative care nurse specialists and consultants has been shown to vary greatly. Only 55% of NHS hospitals have a palliative care team consisting of nurse specialists and consultants. Patients’ needs for specialist palliative care services are not always adequately assessed and, in particular, referrals are often not offered early enough.
Specialist palliative care day therapy facilities offer assessment and review of need as well as a range of physical, psychological and social care interventions such as:

- Medical care including blood transfusions and medication adjustment
- Nursing care, such as bathing and dressing changes
- Emotional and spiritual support
- Social support
- Services for families and carers

Those involved in specialist palliative care have an important function in providing education and training on the principles and practice of palliative care.

9.4 The role of healthcare professionals in general palliative care

9.4.1 GPs and Cardiologists

GP and cardiologists are usually generalists rather than specialists in palliative care and would benefit from a working knowledge of GSF and LCP and basic levels of symptom control. Cardiologists and other hospital consultants should be able to guide colleagues about whether a patient is likely to be in the last year of life (GSF) or whether death is likely or imminent (LCP).

9.4.2 Heart failure nurses

Heart failure nurses are generalists rather than specialists in palliative care and should have a working knowledge of GSF and LCP. Will need basic levels of symptom control and be able to advise colleagues on whether GSF or LCP is applicable. If a patient is likely to be in the last year of life then GSF is useful. If death is likely or imminent then LCP is relevant. Further education and training in palliative care is also very helpful.

Commissioners should ensure the End of Life Care Initiative explicitly includes programmes for heart failure patients and that experts in heart failure have a working knowledge of GSF and LCP.73

Good working relationships with local palliative care specialists and clear understanding of which circumstances would indicate involvement of specialists in palliative care are also important.74

9.5 Modification of medication regimens

While optimisation of pharmacological management of patients with CHF who are close to death is important, several papers report the inadequate use of medication to reduce pain (not necessarily cardiac pain, but pain from joints, muscles, oedema and the like). The resumption of NSAID treatment to ease pain may be offset by additional other medication, despite NSAID use being generally contraindicated for HF patients. Inadequate medication (including use of opioids) is noted amongst those patients suffering from breathlessness or leg oedema. The principles of palliative care for patients with terminal cancer and other severe illnesses are considered to be appropriate for patients dying with CHF.
9.6 Inotrope therapy

The possible use of IV inotrope therapy in severe or near terminal CHF is addressed in a review by Felker and O'Connor. They assert that, on the basis of available evidence, there is no place for routine inotrope therapy. There may be a place for temporary inotrope medication in patients refractory to diuretics, as a bridge to transplantation. They also consider that a case may be made for IV inotrope therapy in palliation of end-stage CHF.

9.7 Complicating problems

With progressive CHF, there is impaired perfusion of all organs and hence, there may occur not only circulatory but respiratory, renal, hepatic or other organ failure. The most important amongst these is the development of hypotension. To maintain the circulation is extremely difficult and some physicians prefer non-interference. The patient is usually administered oxygen, may receive intravenous inotropes and other forms of support. A comprehensive medication review is necessary in case the patient is receiving excessive medication which contributes to hypotension and renal failure.

The presence of persisting dyspnoea at rest may be addressed by use of nitrates in addition to standard medication. Continuous positive airways pressure may be used. The patient may well prefer relief through death. It is necessary to discuss this possibility with patients and carers so that patient choices can be respected. The use of morphine and other opioids has to be considered.

Uncontrolled oedema is occasionally significantly improved, with massive diuresis following change of a diuretic regimen (say, from a large dose of furosemide to a single dose of a thiazide diuretic, utilising a different diuretic pathway).

Respiratory failure may lead to sputum retention. Confusion may occur and hepatic failure may occur. Venous thrombosis and urinary infection are common in patients who are chronically immobilised.

9.8 Sudden cardiac death

Sudden cardiac death may occur at any time in patients with significant CHF, even if it is apparently clinically controlled. The mechanism is usually through ventricular tachycardia degenerating to ventricular fibrillation. Some consider that all patients with an arrhythmic tendency (this really means most patients with CHF) should receive anti-arrhythmic drug treatment in the form of amiodarone. The possible use of an automatic cardioverter defibrillator may also be considered. Neither is usual practice. It is recognised that digoxin is possibly pro-arrhythmic in these patients but the benefits of digoxin in other areas are well documented. Hence, most patients with CHF receive digoxin as standard therapy if they are symptomatic.

In patients who are highly electrically unstable, it is clearly desirable to discuss the problem with the patient, the principal carer and other family members.

9.9 Home, nursing home, hospice or hospital

Some patients quite firmly elect to die at home, provided that there is adequate support. Others clearly appreciate being in hospital or a nursing home / hospice to receive whatever care seems most appropriate at any given moment. This is another area in which knowledge of the patient, the patient’s family and patterns of support in the community is desirable. The major problem in
patients with CHF is the uncertainty of prognosis because of the possibility of sudden
cardiac death. The more gradual deterioration into severe uncontrollable HF usually presents a
clearer prognosis, which can be readily imparted and understood by the family.

9.10 Bereavement support

Standards of bereavement care have been developed by the National Bereavement
Consortium. They proposed a three-component model, outlined below:

Component one
Acknowledgment of the normal grief reaction largely supported by family and friends.
Information offered outlining the usual procedures to be followed after a death and describing
the normal grieving process. This information package includes details on access to more
formalised support if needed.

Component two
If additional support is required, this may be offered through volunteer bereavement support
workers, faith groups, self help or community groups. These support groups need education in
recognising when to refer on to the professional support as outlined in component three.

Component three
Professional bereavement counselors may provide this and clinical care is available through
mental health and psychological services. This component is also available through specialist
palliative care where prospective screening for particularly vulnerable individuals who may
require major bereavement support should be provided.

9.11 Recommendations: palliative care

Table 21. Recommendations: palliative care

1. The principles of palliative care should be applied to patients with advanced CHF similar
to those appropriate for patients dying of cancer
2. Commissioners should ensure the End of Life Care Initiative explicitly includes programmes for
heart failure patients and that experts in heart failure have a working knowledge of GSF and LCP.
3. Mechanisms for support of carers, community groups and health professionals should
be developed
4. Patient’s prognosis and end of life issues should be discussed at all stages of care

9.12 Suggested indicators: palliative care

Table 2. Suggested indicators: palliative care

1. Proportion of patients with advanced CHF managed in line with GSF guidelines
2. Proportion of patients with end stage CHF managed in line with LCP guidelines
10. Confounding problems: psychological, social and environmental factors

It is important to recognise that psychological, social and environmental factors influence the pattern of delivery of medical care, the utilisation of medical services, the availability of supports for patients and the attitudes and behaviours of the patients themselves. The importance of these influences has been progressively recognised in recent years. These confounding problems significantly influence the evidence base upon which best practice recommendations are made. This is because of the selection of patients for entry into clinical trials.

Problems of depression, disability and death markedly influence patients' attitudes, including their attitudes to medical care and their attitude to the way they see the future. Levels of social support and socio-economic status are important in determining outcomes. They also influence the quality of care the patients receive.

It is important to note that patients developing CHF commonly have progressive cognitive impairment which influences not only their adherence to regimens but also may have important implications for patterns of management which have not yet been investigated.

Racial differences have been little studied, although it is recognised that the dispossessed and disadvantaged suffer more from all diseases than do the better off.

The pattern of cardiac failure in women is similar to that in men but death rates are higher because women develop CHF at a later age than do men, consistent with the later development of the underlying heart disease. Age is an important factor in co-morbidity and functional capacity and can influence the effectiveness of many interventions.

These confounding problems are of extreme importance to patients, to carers and to the community. As with so much else, those who need the most often receive the least, because of psychological, social and environmental influences. While the evidence regarding the management of these factors is ambiguous or absent, health professionals should be mindful of these factors in planning and reviewing the care of individual patients.

Appendices

Appendix A: Classification of functional status
New York Heart Association Functional Class

| Class I | No limitations. Ordinary physical activity does not cause undue fatigue, dyspnoea or palpitations (asymptomatic LV dysfunction) |
| Class II | Slight limitation of physical activity. Ordinary physical activity results in fatigue, palpitation, dyspnoea or angina pectoris (mild CHF) |
| Class III | Marked limitation of physical activity. Less than ordinary physical activity leads to symptoms (moderate CHF) |
| Class IV | Unable to carry on any physical activity without discomfort. Symptoms of CHF present at rest (severe CHF) |

Specific Activity Scale (Goldman et al, 1981)

<table>
<thead>
<tr>
<th></th>
<th>Any yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Can you walk down a flight of steps without stopping?</td>
<td>go to 2</td>
<td>go to 4</td>
</tr>
<tr>
<td>2. Can you carry something up a flight of 8 steps without stopping?</td>
<td>go to 3</td>
<td>Class III</td>
</tr>
<tr>
<td>3. Or can you:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(a) have sexual intercourse without stopping?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) garden, rake, weed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(c) walk at 6km/hr on level ground?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Can you carry at least 10kgs up 8 steps?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Or can you:</td>
<td>Class I</td>
<td>Class II</td>
</tr>
<tr>
<td>(a) carry objects that are at least 36 kgs?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) ski, play basketball, squash?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Can you shower without stopping?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Or can you:</td>
<td>Class III</td>
<td>go to 6</td>
</tr>
<tr>
<td>(a) mop floors?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) hang out wet clothes?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(c) clean windows?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(d) walk 4km/hr?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e) play golf walk and carry clubs?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(f) push power lawn mower?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Can you dress without stopping?</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Class III</td>
<td>Class IV</td>
</tr>
</tbody>
</table>
Appendix B: NH&MRC designation of levels of evidence

NH&MRC Designation of Levels of Evidence (1995)

<table>
<thead>
<tr>
<th>Level</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Evidence obtained from a systematic review of all relevant randomised controlled trials</td>
</tr>
<tr>
<td>II</td>
<td>Evidence obtained from at least one properly designed randomised controlled trial</td>
</tr>
<tr>
<td>III</td>
<td>Evidence obtained from any of the following:</td>
</tr>
<tr>
<td></td>
<td>▪ well-designed pseudo-randomised controlled trials (alternate allocation or some other method)</td>
</tr>
<tr>
<td></td>
<td>▪ comparative studies with concurrent controls and allocation not randomised (cohort studies), case-control studies, or interrupted time series with a control group</td>
</tr>
<tr>
<td></td>
<td>▪ comparative studies with historical control, two or more single-arm studies, or interrupted time series without a parallel control group</td>
</tr>
<tr>
<td>IV</td>
<td>Evidence obtained from case series, either post-test or pre-test and post-test</td>
</tr>
<tr>
<td>EO</td>
<td>Opinions of respected authorities based on clinical experience, descriptive studies or reports of expert committees</td>
</tr>
</tbody>
</table>
Appendix C: Tools for assessing functional status and outcomes

Functional status
While commonly a part of quality of life assessments, functional status may be measured independently.

**6 Minute Walk Test** 77,78,79
The 6 Minute Walk Test is an inexpensive and simple test used for objective assessment of exercise capacity of cardiac patients. In this test, patients are asked to walk as fast as they can. The 6 Minute Walk test is of particular use with older patients. It has good reliability, particularly with patients who have CHF.

**New York Heart Association (NYHA) functional classification** 80
Despite some flaws, the functional classifications of the New York Heart Association (NYHA) is a commonly used observer rated classification for quantifying the degree to which symptoms limit the performance of everyday physical activities.

**Minnesota Living with Heart Failure Questionnaire (LIHFE)** 81
The LIHFE has 21 items and assesses physical, socio-economic and psychological impairment in patients with heart failure. It has been widely used, particularly in pharmacological trials.

**Kansas City Cardiomyopathy Questionnaire (KCCQ)** 82
The Kansas City Cardiomyopathy Questionnaire (KCCQ) is another tool for assessing health related quality of life in patients with CHF.

**Specific Activity Scale** 83
This easily administered scale is used to evaluate performance by CHF patients based on the metabolic equivalents of oxygen consumption required for activities the patient actually performs.

Quality of life
Generic measures and disease specific measures represent the two basic approaches to assessing health related quality of life (HRQL). Generic HRQL instruments are designed as outcome measures to allow comparisons across populations and interventions, while disease specific HRQL instruments focus on symptoms and problems relating to a particular disease and are thus used as outcome measures in specific populations.

**SF-36**
A generic measure, the Medical Outcomes Study Short Form 36 (MOS SF-36) 84 is a shortened version of the Medical Outcome Survey (MOS). It has 36 items measuring eight health concepts, namely: physical functioning, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems and mental health.

**SF12**
This 12-question survey generates an abbreviated health profile consisting of two summary measures describing health-related quality of life. The SF-12 has been shown to yield summary physical and mental health outcome scores that are interchangeable with those from the SF-36 in both general and specific populations 86.
Psychological functioning
Several instruments are available to measure specific psychological states, such as anxiety and depression. Most are generic tools. Some of the more commonly used questionnaires include the following:

Hospital Anxiety and Depression Scale (HADS)
The HADS is a 14 item scale with separate subscales for anxiety and depression. Developed for use with medically ill patients in hospital, it is commonly used as a screening tool to detect psychological disturbance.

State Trait Anxiety Inventory (STAI)
The STAI is a 40 item questionnaire consisting of a 20 item scale assessing state (current) anxiety and a 20 item scale measuring trait (general) anxiety. It can be completed quite quickly and has been used in previous studies of cardiac patients.

Beck Depression Inventory (BDI)
The BDI is a 21 item scale for measuring depression. A short version has also been produced. It is commonly used to assess depression in cardiac patients.

Cardiac Depression Scale (CDS)
The CDS was produced to provide a more sensitive depression scale for cardiac patients. Its 26 items reflect the range of depressive symptoms seen in cardiac patients.
Appendix D: Integrated Care Pathway for Heart Failure

Patients with symptoms of heart failure

Initial assessment
- **History**: Breathlessness, fatigue and/or previous MI
- **Examination**: Pulmonary oedema, increased JVP, ankle oedema, tachycardia murmur, gallop rhythms
- **Investigations**: Abnormal ECG, LHV, cardiomegaly or pulmonary

High suspicion of heart failure?

Refer for Echocardiogram (or BNP test, if available)
Start loop diuretic if clinically indicated

Confirmation by Echo
- **Yes**: Start treatment (See treatment algorithm)
- **No**: No systolic dysfunction – ACE I of no proven

Remove Aggravating Factors:
Stop/withdraw NSAIDS, Steroids, Diltiazem, Verapamil

Heart Failure Start treatment
(See treatment algorithm)

Specialist Advice needed

COMMUNITY HEART FAILURE SERVICE (CHeFs)
Clinical assessment. Case management, Review/titration of drug therapy, education and support, home visits, and/or referral to palliative care (See Clinical Standards)

Hospital Referral Criteria
- Symptomatic bradycardia or tachycardia
- Respiratory rate > 30
- Oxygen saturation < 80% on room air
- Systolic blood pressure > 200 or < 85mm Hg
- Worsening dyspnoea
- Orthopnoea
- Paroxysmal nocturnal dyspnoea
- Severe pulmonary oedema, effusion or pneumonia
- Raised JVP >12cm H2O
- Non-positional near syncope
- Unstable angina
- Renal failure
- Refractory hyperkalaemia
- ECG changes consistent with ischaemia
- New onset atrial fibrillation
- Worsening ventricular ectopy or worsening ejection fraction
- Angiogram showing new onset or severe CAD

Cardiologist Review
Additional diagnostic tests if appropriate

Patient admitted with heart failure

Hospital-based Heart Failure Clinic
Case management, titration of drug therapy, continuing education and support, and/or referral to palliative care, home visits
When stabilised refer to GP and/or CHeFS

Patient discharged
Appendix E: Guidelines for diagnosis and management of Heart Failure

Heart Failure - Assessment Algorithm in Primary Care

Clinical assessment of patient, history and hospital records suggest heart failure

Diagnostic Investigations
- 12 lead ECG
- Chest X ray
- BNP or NTproBNP tests (Normal < 100pg/ml)

ECG abnormal ? (abnormal Q waves, Left bundle branch block )

Chest x-ray showing pulmonary oedema or cardiomegaly

No

Normal

Yes

BNP or NTproBNP > 100pg/ml *

Imaging by Echocardiography (to confirm heart failure)

Echocardiography** shows moderate or severe LV dysfunction? EF <40%

Yes

No, inconclusive or not known

Heart Failure Unlikely

Remaining strong clinical suspicion of heart failure

Other Recommended Tests (primarily to exclude other conditions)
- FBC, U&E’s, TFT’s, LFT’s, glucose & lipids, peak flow or spirometry

Probability of heart failure high
Are you confident of diagnosis?

Yes

No

Heart Failure
Start ACE inhibitor
Consider Beta blockers
Spironolactone
Diuretic

Refer for further investigation

New York Heart Failure Association Classification

Class 1 No symptoms on ordinary physical activity
Class 2 Mildly short of breath on ordinary activity eg. climbing one flight of stairs
Class 3 Markedly symptomatic on minimal exercise eg. walking room to room
Class 4 Inability to carry on any physical activity without symptoms. Short of breath at rest

* Note: BNP Test is useful in excluding a diagnosis of heart failure.
** Note: Echocardiography should be carried out in all patients to confirm a diagnosis of heart failure
Heart Failure – Treatment Algorithm in Primary Care

1 See use of ACE inhibitor algorithm. If not tolerated, consider A 2 receptor antagonist combination therapy/digoxin

2 Indicated in NYHA class I-III heart failure. Extreme caution required in initiating beta-blocker; best done under specialist direction

3 Electrical cardioversion may be indicated; other specialist drugs eg. amiodarone may be indicated

4 Refer to cardiologist; coronary angiography and bypass surgery may be indicated

5 Indicated in NYHA class III/IV. Dose 25mg once daily – Must monitor U/E’s Stop if renal function deteriorates and or if potassium rises rapidly and is >5.5mmols

6 Other specialist therapy may be indicated as outpatient or inpatient

Suspected Left Ventricular Systolic Dysfunction

-Confirm diagnosis by Echocardiography
-Stop (if possible) aggravating drug eg. NSAIDS, most calcium channel blockers
-Exclude precipitating factors eg anaemia infection and thyroid disease

If delay in obtaining ECHO treat as per protocol until ECHO available

If pretreated with diuretics add these agents at this stage

- Angiotensin converting enzyme inhibitor (1)

Atrial Fibrillation

-Digoxin plus
-beta blocker (2) if heart rate not controlled
-Wafarin
-Referral recommended (3)
on referral replace digoxin with amiodarone, check TFT & LFT

Angina

-Consider Beta-blocker (2)
-Oral nitrate and/or
-Amlodipine and/or
-Referral recommended(4)

Signs of Water Retention

-Loop Diuretic eg. furosemide 40mg od orally

Persisting symptoms but no signs of fluid retention (NYHA class III/IV)

-Refer to specialist (6)
-Digoxin and/or
-Spiromolactone (5)
-Beta blocker (2)

Persisting signs of fluid retention

-Consider spironolactone (5) and/or
-Increase dose of loop diuretic eg furosemide up to 80mg OD and/or
-Consider digoxin and/or
-Consider referral (6)

Suspected Left Ventricular Systolic Dysfunction

-Digoxin plus
-beta blocker (2) if heart rate not controlled
-Wafarin
-Referral recommended (3)
on referral replace digoxin with amiodarone, check TFT & LFT

Symptoms relieved (NYHA class I-III)

-continue existing therapy

If pretreated with diuretics add these agents at this stage

Angina

-Consider Beta-blocker (2)
-Oral nitrate and/or
-Amlodipine and/or
-Referral recommended(4)

Signs of Water Retention

-Loop Diuretic eg. furosemide 40mg od orally

Persisting symptoms but no signs of fluid retention (NYHA class III/IV)

-Refer to specialist (6)
-Digoxin and/or
-Spiromolactone (5)
-Beta blocker (2)

Persisting signs of fluid retention

-Consider spironolactone (5) and/or
-Increase dose of loop diuretic eg furosemide up to 80mg OD and/or
-Consider digoxin and/or
-Consider referral (6)
Confirmed left ventricular dysfunction

Specialist advice required before starting ACE inhibitor

If any of the following are present
- Creatinine > 200mmol/l
- Urea > 12mmol/l
- Systolic arterial pressure < 100mmHg
- Diuretic dose. Furosemide 80mg or equivalent
- Known or suspected Renal Artery Stenosis
- Frail elderly

Suitable for treatment in the community

Step 1

- Stop potassium supplements/potassium sparing diuretic (risk of hyperkalaemia)
- If possible stop NSAID (risk of renal dysfunction)
- Advise patient re. risk of dizziness lightheadedness, especially on standing up
- Start with low dose eg. Lisinopril 2.5mg OD
- Titrate up to lisinopril 20 mg in stages subject to tolerability BP response and renal function over one month

Step 2

Review patient in 1 week

If adverse effects

Specialist Referral

If adverse effects

Step 3

Review patient after 1 month

- Check U & E’s
- Check for adverse effects eg. symptomatic hypotension, renal dysfunction/hyperkalaemia ie. rise in urea to >15 mmol/l, creatinine to >230 mmol/l or potassium to >5.5mmol/l

Contraindications to ACE Inhibitors
- LV outflow tract obstruction ie. AS or HOCM
- Severe renal failure
- Hypotension Systolic BP < 90 mmHg
- Renal artery stenosis
- Pregnancy or lactating mothers
Appendix F: Referral Pathway for Specialist Palliative Care

Patient meets Criteria for Referral*
If URGENT contact Specialist Palliative Care Team Directly

1. Hospital In Patient
2. Hospital Out Patient
3. Home / Nursing home

Referral to Hospital Palliative Care Team (HPCT)
Referral to Community Palliative Care Team (CPCT)

Referral to Specialist Palliative Care Inpatient Unit/Hospice, +/- Day Care
Criteria for Referral

All cardiac patients being referred to the palliative care team MUST:

- Have been reviewed by the heart failure team
- Know they have a diagnosis of heart failure
- Agree to the referral, both patient and medical team

Routine referrals will be contacted within 2 working days to arrange an assessment.

Criteria for Urgent Referral.

For urgent referrals, direct contact with the palliative care team is needed to discuss each situation individually.

- Difficult psychological/physical symptoms causing distress and not responding to current management
- Rapidly deteriorating condition

Referral is recommended if one or more of the following apply:

1. Symptomatic (e.g. breathless at rest or minimal exertion) despite optimal treatment
2. Heart failure patients when hospital admission may not be the best/only/preferred option, or for whom palliative care (hospice, day care, hospital inpatient or community care) may be of benefit, either immediately or in the future
3. Optimal therapy but continuing or deteriorating physical and/or psychological symptoms. Where only psychological issues are present consider referral to clinical psychology.
4. Where the family or carer(s) would benefit from support, either immediately or in the future (including bereavement)
5. Where the patient has had two or more previous admissions for heart failure within the last six months

Please RING AND DISCUSS if you are uncertain whether referral is appropriate

The following should have already taken place:

- Open discussion with both patient and family/carers (this can be challenging; if difficulties are encountered these should be discussed with palliative care so that the process can be facilitated)
- First line management for identified symptom problems, as per established guidelines

Referral process

Specialist palliative care input may come in a number of ways:

1. Telephone advice for specific symptom management problems for healthcare professionals in the hospital or community setting.
2. One off assessment from specialist palliative care at home with follow up by generic primary care services.
3. One off assessment/input in the secondary setting, either on the wards, or in outpatients with follow-up predominantly by heart failure services.
4. Ongoing support from community palliative care services (regular home visiting), with all other hospice services available. This would be for patients who have particularly complex or multiple symptoms (physical, psychological, social, or spiritual), and when a mutual decision has been taken against active, interventional treatment.
5. Continuing support from hospital palliative care services whilst the patient remains an inpatient, with ongoing specialist palliative care referral when discharged to another setting, e.g. home or hospice if referral appropriate.
Appendix G: List of figures

Figure 1. Admissions for heart failure in Lewisham (2000 - 2006) 18
Figure 2. Age Standardised of admission for heart failure in South London 18
Figure 3. Age Standardised mortality rates for heart failure in South London 19

Appendix H: List of tables

Table 1. Incidence of heart failure in Lewisham 17
Table 2. Prevalence of heart failure in Lewisham 17
Table 3. Admissions for Heart Failure in Lewisham 18
Table 4. Classification of CHF 24
Table 5. Recommendations: diagnosis and assessment of CHF 25
Table 6. Suggested indicators: diagnosis and assessment of CHF 25
Table 7. Levels of evidence for effectiveness of treatments (summarised) 31
Table 8. Levels of evidence for pharmacological management of CHF 31
Table 9. Recommendations: pharmacological management of CHF 33
Table 10. Suggested Indicators: pharmacological management of CHF 33
Table 11. Levels of evidence for effectiveness of CDM of CHF 35
Table 12. CHF management: prospective randomised controlled trials 37
Table 13. Recommendations: chronic disease management of CHF 42
Table 14. Proposed indicators: chronic disease management of CHF 43
Table 15. Recommendations: staff and facilities for CDM of CHF patients 44
Table 16. Continuum of care 45
Table 17. Recommendations: exercise and activity programme 49
Table 18. Suggested indicators: exercise and activity programme 49
Table 19. Recommendations: self care 52
Table 20. Suggested indicators: self care 52
Table 21. Recommendations: palliative care 57
Table 22. Suggested indicators: palliative care 57
References

5. de Sousa LC, Lemic N. Identifying the need for a community heart failure service in Bromley and Lewisham. Sept 2003


71. Gold Standards Framework. 2007
72. Liverpool Care Pathway. Marie Curie Palliative Care Institute. 2001
73. Department of Heath, Healthcare Commission Review. Pushing the Boundaries - Improving Services for Patients with Heart Failure. 2007
74. WHO. Palliative care: the solid facts at better palliative care for older people. www.euro.who.int/document/E82933