

Living and dying with advanced heart failure: a palliative care approach

March 2008

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Foreword



As this highly significant report acknowledges, the Coronary Heart Disease (CHD) and Stroke Task Force recommended back in 2001 that provision should be made to meet the palliative care needs of people with end-stage heart failure. A succession of reports from the Scottish Audit of Surgical Mortality has highlighted the plight of those with conditions such as end-stage heart failure dying in acute hospitals, with a worse prognosis and poorer quality of life than many cancer patients, but with no access to the benefits that palliative care could bring. We now have SIGN Guideline 95 on the management of chronic heart failure, with a section on palliative care that includes a clear recommendation that a palliative care approach should be adopted by all clinicians managing patients with chronic heart failure *in the early stages of the disease* (my emphasis).

People with heart failure and their carers, this report tells us, may complain that they are uninformed about their condition, are excluded from decision-making and feel that control of their lives is taken away from them. This is the polar opposite of the approach we are encouraging to the management of long term conditions. The aim should be to regard people and their carers as equal partners in their care, to recognise the expertise which they inevitably develop in living with these conditions and to help them achieve the best quality of life possible.

The key to this, as to so much in good medicine, lies in communication, whether with people with heart failure and their carers, or among the wide range of agencies involved in the provision of care. Adoption of a palliative care approach is central to the promotion of good communication.

There are a number of ways we can take forward implementation of the recommendations in the report. We will incorporate the essence of them in the refreshed version of our CHD & Stroke Strategy, a consultation version of which we will be issuing shortly. The heart failure report highlights the role of both the cardiac Managed Clinical Networks and the palliative care MCNs in taking forward implementation locally, and I know they will be able to look for support, as needed, from the National Centre for the Treatment of Advanced Heart Failure. The recommendations will also contribute to the work which NHS Quality Improvement Scotland is beginning to undertake on translating the various SIGN Guidelines on heart disease, including SIGN 95, into clinical standards and other mechanisms, such as the heart failure audit.

I fully endorse what I think is one of the most important statements in the report: that the inherent unpredictability of the disease is not sufficient justification for a failure to introduce appropriate palliative care to the ongoing management and support of those with heart failure.

A handwritten signature in black ink that reads "Harry Burns". The signature is written in a cursive, slightly slanted style.

DR HARRY BURNS
Chief Medical Officer for Scotland

Preface



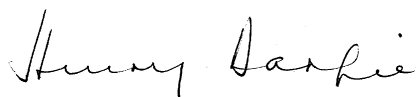
This document is timely because palliative care has been on the periphery of the management of heart failure for far too long. Medical research has yielded a rich harvest of new technologies, both pharmacological and interventional, which have the potential substantially to improve survival. But patients admitted to our hospitals with worsening heart failure still stand only a 60% chance of being alive just one year later. This is because, in 'real life' clinical practice, patients are older, often have multiple co-morbidities and rarely achieve the high level of concordance with their care plans reported in clinical trials. There is an important message here because recent audit data suggests that outcomes in heart failure are generally poorer in the UK countries as compared to other developed nations. And audit data from England and Wales show that the implementation of evidence based management of heart failure is variable and generally suboptimal, suggesting that the continuing high mortality and morbidity

from and re-hospitalisation for worsening heart failure could, in part, be related to poor quality of care. While the recently funded QIS audit of heart failure care will soon provide data specifically from Scotland it would be foolish to assume that our patients fare any better.

Of course what all patients with heart failure deserve is a coherent care plan based on an accurate diagnosis and assessment of the severity of their heart failure within a robust and integrated programme for heart failure implemented across all sectors of the healthcare system. Central to such a programme should be improving not only the prognosis for our patients but also the quality of their lives. Palliative care, therefore, should be a core component of this process since helping people to feel better, eventually, will be more important than extending life.

An important recommendation of this report is that the implementation of the palliative approach should be through the present heart failure multidisciplinary team in association with the specialist palliative care system. This will help ensure that patients with advanced heart failure will be properly reassessed to confirm that palliation is the appropriate choice among an increasing number of strategies including the better application of best medical treatment, devices, other interventions and conventional and transplant surgery. Acquisition of basic palliative medicine skills by a wider group of healthcare professionals also will protect the specialist palliative care services from being overstretched by this new constituency of patients.

Living and dying with advanced heart failure: a palliative care approach clearly describes the potentially extensive scope of palliative care in heart failure and makes many sensible and practical recommendations. But the scale of their implementation will be determined by fundholders. Inevitably, translating these recommendations into practice will mean making choices about where gains can be made most effectively and rewardingly for patients. For those patients who, despite our best efforts, are close to the end of their lives, many will agree that making the quality of their life our primary aim would be an excellent start.



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1. Executive summary

This report highlights some of the significant challenges in the journey faced by patients and carers living and dying with advanced heart failure, and makes recommendations regarding key elements of good practice and the delivery of more effective services which might help to address their palliative care needs.

Compared to many cancer patients, those with heart failure have a worse prognosis, poorer quality of life, and more limited access to social services and to palliative care support. 50% of patients with advanced heart failure die within a year of diagnosis and 50% of the remainder within five years. It is difficult to predict individual prognosis, largely because as many as 50% of heart failure patients die suddenly and unexpectedly.

Most patients with advanced heart failure have a combination of medical, social, psychological, spiritual and emotional needs which are best addressed by a combination of ongoing optimum active cardiological treatment and the early and phased implementation of a palliative care approach by all professionals routinely involved in their care. Specialist palliative care services should be accessed when required for the minority who have complex needs.

All patients with advanced heart failure and their carers should have the opportunity to discuss and understand the diagnosis and its implications, as well as to be involved in treatment plans and to exercise informed choice where appropriate. Wider recognition of heart failure as a terminal condition which adversely affects the quality of life of patients and carers would facilitate better service provision. Improved communication skills and greater openness on the part of clinicians in discussing sensitive issues around prognosis and end of life issues would enhance the quality of life of patients and families and later contribute to the well-being of the bereaved.

A shared care approach is needed, with the key roles undertaken by primary care and cardiology services and additional services such as specialist palliative care accessed as required. Effective communication and collaboration across all sectors and disciplines, including out of hours care, and effective co-ordination of care by a named individual such as a heart failure specialist nurse or other suitably trained health professional, are crucial in addressing the inherent difficulties and uncertainties of the patient journey. Reciprocal opportunities to share knowledge, experience and educational opportunities and to gain greater understanding of the management of patients with advanced heart failure and of relevant palliative care strategies should be available to all health and social care teams involved. Consideration should be given to issues such as workforce planning, reorganisation of existing services and the provision of additional resources in order to implement the recommendations contained within this report.

2. Background

2.1 Policy framework

It is the policy of the Scottish Government that good palliative care should be available to anyone suffering from a progressive, incurable condition, and previous Scottish Executive publications refer specifically to the needs of people with heart failure in this context¹. The report by Professor David Kerr² and the Scottish Executive response, *Delivering for Health*³, highlighted the implications for Scotland's healthcare of an ageing population and the challenges arising particularly from the management of multiple long-term conditions in the community. The Scottish Government *Better Health, Better Care: Action Plan*⁴ further develops this agenda with a commitment to developing a national palliative care Action Plan in 2008.

The palliative care needs of people with heart failure have been acknowledged in policy developments throughout the UK^{5,6,7}. In Scotland, a key development has been the publication of the Scottish Intercollegiate Guidelines Network (SIGN) and NHS Quality Improvement Scotland *National Clinical Guideline: 95 Management of chronic heart failure*⁸.

2.2 Purpose of this report

This report is a policy document outlining key issues and themes which should be considered in the ongoing development of local strategies for the palliative care of patients with advanced heart failure. A limited amount of detail is included, and the report functions mainly as a signpost to key issues and to further sources of information. Although the document and its recommendations focus on patients with advanced heart failure, many of the principles outlined may apply equally to those at earlier stages of the disease.

The report is based on existing evidence and on evidence informed good practice:

- the report's content is referenced wherever possible to published opinion and peer-reviewed research
- where no such evidence is available, the statements and recommendations in the report are also based on the experience and opinion of members of the working group, who are all experts in their fields, and of additional experts who contributed through the consultation process
- the report is underpinned by awareness on the part of the working group and those who contributed through the consultation process of relevant local and regional guidelines
- the report contains an Appendix with general information on symptom management, but does not purport to be a comprehensive symptom control guide.

The report aims to provide clarification for clinicians and strategists regarding the principles of palliative care and why it is important in the management of advanced heart failure. It is relevant to policy makers and planners as well as to clinicians, and is intended to be of use to professionals across all sectors, specialties and disciplines who are involved in the care of people with advanced heart failure and their families, as well as to Managed Clinical and Managed Care Networks, Community Health Partnerships, NHS Boards, local authorities and other relevant bodies.

3. What is heart failure and how is it treated? - the clinical perspective

3.1 What is heart failure?

Heart failure is a chronic progressive condition resulting from weakness of the heart muscle. The commonest causes of heart failure in the western world are coronary artery disease and hypertension.

3.2 Facts and figures

Currently 3% of the UK population over 45 years old are thought to be affected by heart failure⁹ with figures for the over 75s rising to 7%, and to 15% for the over 85s. In 2007 it was estimated that as many as 100,000 people in Scotland were living with heart failure¹⁰. With an increasingly elderly population, it is thought that the prevalence of heart failure could increase by as much as 70% by 2010¹¹.

In most cases heart failure is incurable. Death may occur within a few weeks of diagnosis, but some patients survive for ten or more years. Commonly quoted mortality data are that 50% of patients in NYHA class IV (symptoms at rest, see table 1) despite optimal medication die within a year and 50% of the remainder die within 5 years¹². More recent data suggests improved survival, mainly in relatively young patients able to tolerate optimum treatment. The mortality rate will decline further in eligible patients as devices such as implantable cardioverter defibrillators (ICDs) and pacemaker therapies are more widely used¹³.

3.3 Disease trajectory

A particular feature of heart failure is that up to 50% of patients die suddenly and unpredictably at any stage during the course of the disease^{14,15}, although the increasing use of automated implantable defibrillators will impact on these figures. For the majority of the remaining patients, disease progression is likely to follow the pattern below:

- the onset of symptoms (a combination of breathlessness, fatigue and oedema)
- an improvement in symptoms following the initiation of standard treatment
- a period of symptom stability enabling many patients to return to some level of normal activity
- the return of symptoms which become increasingly resistant to treatment: this characterises the stage of advanced heart failure (3.6)
- progressive deterioration marked by episodes (possibly reversible) of decompensation
- terminal stage: the last few days of life (3.7).

Symptomatic improvement in response to treatment and the subsequent deterioration can be usefully assessed using the New York Heart Association Functional Classification scale (see Table 1).

Table 1 : New York Heart Association (NYHA) Classification

Class	Symptoms
I:	No limitation: ordinary physical exercise does not cause undue fatigue, dyspnoea or palpitations
II:	Slight limitation of physical activity: comfortable at rest but ordinary activity results in fatigue, palpitations or dyspnoea
III:	Marked limitation of physical activity: comfortable at rest but less than ordinary activity results in symptoms
IIII:	Unable to carry out any physical activity without discomfort: symptoms of heart failure are present even at rest with increased discomfort with any physical activity

(The Criteria Committee of the New York Heart Association¹⁶)

The overall progression of heart failure, compared to the trajectories of cancer and dementia/frailty, is shown in Figure 1.

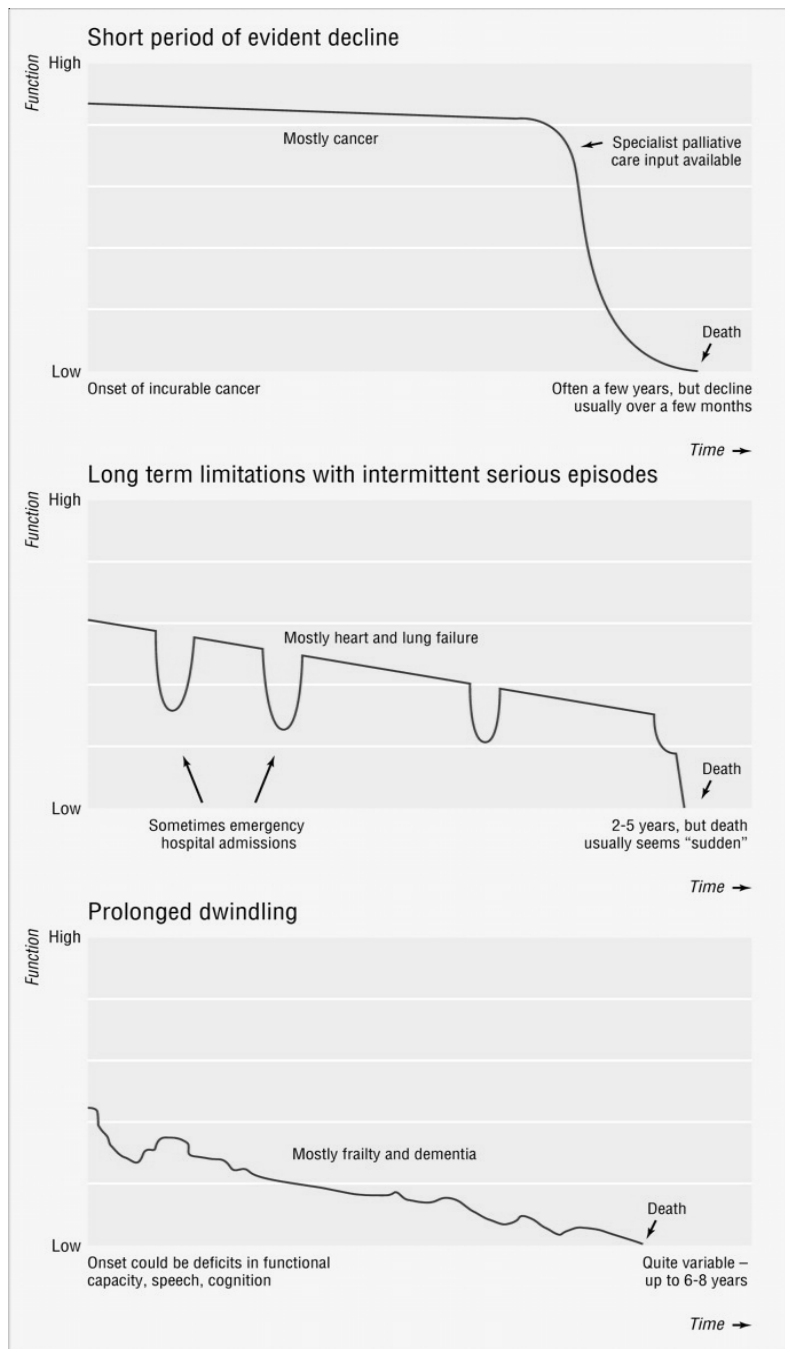


Figure 1: Typical illness trajectories for people with progressive chronic illness. Murray et al 2005¹⁷. Adapted from Lynn & Adamson 2003¹⁸. Reproduced with permission from BMJ Publishing Group Ltd and RAND Corporation, Santa Monica, California, USA.

3.4 Prognostic uncertainty

The rate of progression of heart failure in individual patients is unpredictable. Three key factors contribute to the uncertainties experienced:

- cardiac events which commonly precipitate hospitalisation, such as myocardial infarction, unstable angina and atrial fibrillation, can occur at any time
- sudden death may occur at any point in the disease trajectory
- it can be difficult to identify when a patient is terminally ill.

3.5 Conventional treatment strategies

Optimal treatment relieves symptoms, improves prognosis and can temporarily reverse the effects of myocardial damage. Disease progression is slowed, not halted.

3.5.1 Drug treatments

Drug treatment is based on a combination of medications which are incrementally titrated up towards the

optimum dosage. This process may take several months. It involves finding a balance between achieving the desired dosage of each drug and avoiding or minimising side effects, including unacceptable deterioration in renal function (see Appendix 2 'Examples of approach to reassessment of medication in advanced heart failure' and Appendix 1, 'Renal impairment'). Comprehensive details of treatment and management of heart failure are provided in local, national and international guidelines.

3.5.2 Additional treatments

Additional forms of treatment are appropriate for some patients:

- surgery for coronary artery or valvular disease
- specific treatment protocols for those hospitalised with episodes of acute decompensated heart failure
- implantable cardioverter defibrillators (ICDs)
- cardiac resynchronisation therapy
- arrhythmia management.

Lifestyle changes including dietary measures, fluid adjustment, and exercise programmes may be recommended.

3.5.3 Treatment of co-morbidities

Heart failure, especially in the elderly, is characterised by a high prevalence of co-morbidities (see Table 2). Most patients have three or more additional conditions. These may be more distressing than the heart failure itself, and often adversely affect quality of life and prognosis¹⁹. Treatment of co-morbidities may be neglected when treatment of heart failure is prioritised^{20,21}.

Table 2: Common co-morbidities in heart failure

Anaemia
Chronic renal disease
Chronic obstructive pulmonary disease
Cognitive dysfunction
Depression
Diabetes
Peripheral vascular disease
Stroke disease

3.6 Advanced heart failure

Advanced heart failure is defined as the presence of severe symptoms and poor exercise tolerance (NYHA Functional Class III or IV) which have persisted for at least three months despite attempts to optimise standard therapy²². In practice, the onset of this stage is identified with hindsight but it nevertheless represents a watershed in the patient's management. Many patients face recurrent episodes of hospitalisation, usually caused by worsening heart failure and its complications, or by problems relating to medication or to a co-morbidity²³. Treatments outlined above (3.5.2) may be appropriate for some of these patients. Implementation of a palliative care approach will complement conventional treatment (see 5.3).

3.7 The terminal stage of heart failure and diagnosing dying

Following an indeterminate period of symptomatic deterioration, usually lasting from a few months to a year or two, the patient enters the terminal stage of their illness. This may last several days or more and may be the continuation of a gradual process of deterioration or be triggered by a specific event such as an acute coronary syndrome or a chest infection.

As with other progressive diseases there are no specific indicators that a patient with heart failure is close to death. Table 3 lists common findings in patients who are terminally ill. These are not diagnostic criteria,

and not all will occur in any given case. Where an increasing number are found to be present, this is likely to herald the onset of the terminal stage.

Table 3 Common findings in heart failure patients entering the terminal stage

Generic indicators:

- unable to take oral fluids/medication
- increasingly withdrawn or unresponsive
- increasingly weak/exhausted
- bed-bound.

Pointers related to advanced heart failure:

- previous hospitalisation within the past few months or frequent out-patient visits without significant improvement
- no further interventions likely to improve the patient's condition
- no reversible cause of current deterioration
- unresponsive to maximum tolerated medication
- deteriorating renal function
- anaemia
- hyponatraemia
- breathless at rest or on minimal exertion (NYHA class IV)
- hypotension and persistent tachycardia at rest
- skin breakdown with exudation from oedematous lower limbs
- delirium
- life threatening co-morbidity (eg COPD, critical limb ischaemia).

There may be failure to recognise or reluctance to accept that this point has been reached for several reasons:

- the need to ensure that the current situation is irreversible (the final stage of heart failure can present in different ways, and the patient may sometimes respond to treatment)
- varying the combination and dosages of conventional heart failure medications may result in temporary improvement for some patients
- the usual curative focus of medical care, particularly in the acute sector, means that some professionals may be reluctant to accept that no further benefit will accrue from any further medical interventions.

Careful assessment by the multi-disciplinary team is therefore essential. Recognition and agreement by members of the healthcare team that a patient is terminally ill allows the timely planning and implementation of appropriate care (see 6.4).

4. *Living and dying with heart failure - the patient and carer experience*

4.1 What is the impact of advanced heart failure on patients and carers?

The effects of advanced heart failure are severe and disabling. Patients have a poorer quality of life than those with most other chronic progressive diseases²⁴. There is progressive physical limitation from an early stage of the disease. Even simple daily tasks become difficult, time consuming or impossible. The result is social isolation, with major implications for family relationships and the role of carers. In addition, co-morbidities complicate care management and add to the symptom burden. Patients and carers often have to manage a complex and ever-changing regimen of drugs and side effects are common.

4.2 Continuity and co-ordination of care

Patients usually present initially to their general practitioner with breathlessness or ankle swelling and may then be referred to hospital for investigation or specialist advice. For most of the time, they are cared for in the community by their primary care team, supported if appropriate and where available by a heart failure specialist nurse. Recurring episodes of hospitalisation are common, however, and some patients are diagnosed only as a result of an emergency hospital admission. Hospital care is more likely to be provided by a general physician or geriatrician rather than by a cardiologist, and patients will not necessarily be cared for by the same hospital team on subsequent admissions. The number of different professionals involved often results in fragmented and unco-ordinated care.

4.3 Quality of life issues

The combined impact of physical symptoms, co-morbidities, and the psychological and social results of unco-ordinated care and poor communication all contribute to the poor quality of life of patients with heart failure²⁵ (see Chapter 6). Patients and families are often poorly informed about heart failure, its treatment and prognosis. This may result in:

- insufficient opportunities for patients and carers to discuss and understand the diagnosis and its implications
- insufficient involvement of patients and carers in treatment planning
- limited opportunities to make informed decisions and express preferences about goals of care and preferred place of death
- reduced opportunities to address 'unfinished business' including practical and legal issues and to receive psychological and spiritual support
- lack of information on eligibility for welfare benefits
- less likelihood of receiving appropriate end of life care delivered in a proactive way.

5. Introducing palliative care

5.1 What is palliative care?

Palliative care is a comprehensive and proactive approach to the care of patients whose disease is not responsive to curative treatment. The World Health Organization describes palliative care as:

‘... an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patients illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life ... and includes those investigations needed to better understand and manage distressing clinical complications.’

(World Health Organization²⁶)

Effective palliative care consists of a combination of disease management, symptom control and psychosocial care. It includes, but is not synonymous with, terminal care. Its focus is quality of life, including quality of dying, and it aims to address the whole person, not just the disease. It relies heavily on a holistic approach and on open and sensitive communication with patients, informal carers and professional colleagues. Although developed for patients with cancer, the principles and practices of palliative care are generic: they are equally appropriate for patients with other progressive incurable diseases, including advanced heart failure.

5.2 Why do people with advanced heart failure need palliative care?

The advanced stages of heart failure can have a devastating effect on the quality of life of patients, which is often characterised by complex co-morbidities and frequent admissions to hospital^{14,27,28}. Compared to patients with cancer, those with advanced heart failure have a worse prognosis and less access to social and financial support. In addition, they are less well informed about their condition and have less opportunity to address end of life issues^{25,29}. Symptom relief has been shown to be inadequate in a majority of cases³⁰. Despite their multiple and frequently complex needs, they and their carers often have limited access to the benefits of a palliative care approach^{31,32}.

5.3 When should palliative care be introduced?

Good communication (see 6.1) is essential and is needed from the time that heart failure is diagnosed. The other components of a palliative care strategy (see 6.2, 6.3 and 6.4) should be introduced when required. Optimum benefit for patients with advanced heart failure can be achieved by a combination of conventional treatment and palliative care³³. Palliative care should be introduced gradually and seamlessly, overlapping and complementing active treatment¹⁷ (See Figure 2).

As a practical guide, the transition between different stages of the NYHA Classification (Table 1), may provide a trigger to consider the introduction or increase of palliative support into the management strategy as conventional treatment becomes ineffective.

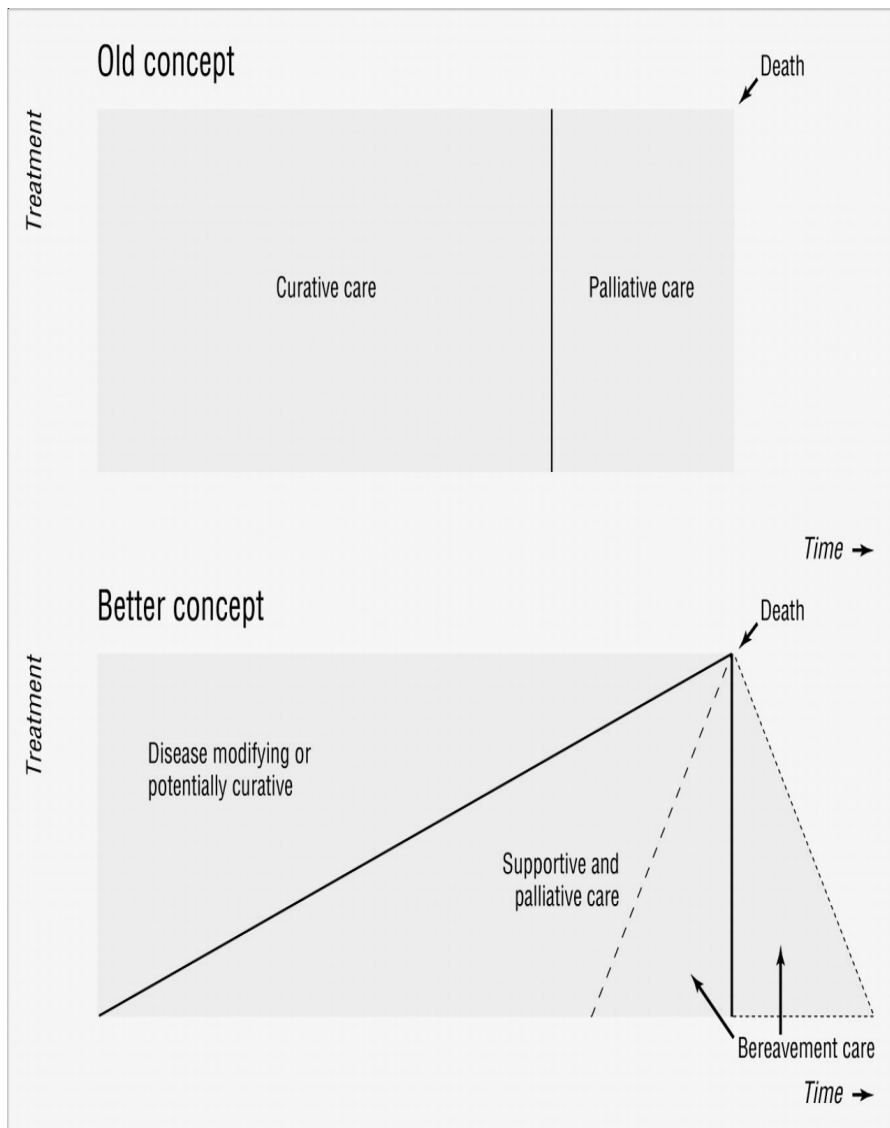


Figure 2: *Appropriate care near the end of life*
Murray et al 2005¹⁷. Adapted from Lynn & Adamson 2003¹⁸.
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5.4 Providing palliative care for patients with advanced heart failure

By definition, at this stage of the disease symptoms are becoming resistant to conventional treatment. As a result palliative care symptom control measures may be needed. In addition the need of patients and carers for psychosocial support also increases and should be addressed.

The level of palliative care provided may be either generalist or specialist depending on the needs of the patient and their family. General palliative care is appropriate for the majority of patients with advanced heart failure and should be incorporated into routine clinical care³⁴.

General palliative care includes provision of:

- information for patients and carers, with 'signposting' to relevant services
- accurate holistic assessment of patient needs
- co-ordination of care teams in and out of hours and across boundaries of care
- basic levels of symptom control
- psychological, social, spiritual and practical support
- open and sensitive communication with patients, carers and professional staff
- referral for specialist palliative care when necessary.

(National Institute for Clinical Excellence³⁵)

5.4.1 Referral for specialist palliative care

For people with complex needs specialist palliative care is provided by members of multi-professional palliative care teams, including consultants in palliative medicine, clinical nurse specialists, chaplains, social workers, pharmacists and appropriate allied health professionals. Specialist palliative care teams are available to advise colleagues in primary and secondary care as well as offering a specialist assessment or direct involvement in patient care if appropriate. In all care settings, an awareness of when to seek advice or refer can be crucial in ensuring that the palliative care needs of patients and families are met appropriately. Referral to specialist palliative care should not be regarded as 'handing over' the patient, but as an opportunity for the palliative care team to provide additional support to patients and carers and to their usual healthcare team as and when necessary at crucial points in the disease trajectory³⁶. It has been estimated that no more than 10% of people with palliative care needs, including those with heart failure, are likely to require specialist palliative care³⁷.

Following referral to specialist palliative care the service may offer:

- a ward consultation by a palliative care doctor or clinical nurse specialist
- a visit for assessment or a short period of intervention by the specialist team in a hospital or community setting
- assessment in a specialist palliative care symptom control outpatient clinic
- assessment at a specialist palliative care day unit
- a short admission to an inpatient specialist palliative care or hospice unit.

Referral for a specialist palliative care assessment should be considered for the following:

- patients with difficult symptom control and / or complex physical or psychological family or social needs
- patients and families needing additional support with issues relating to end of life care including advance care planning and decisions about treatment and care.

6. The palliative care approach in advanced heart failure

6.1 Communication

Good communication is a central tenet of palliative care. Professionals need to:

- establish a process of open and interactive discussion with patients and carers
- explain the nature of the condition and agree a management plan
- acknowledge and discuss the unpredictability inherent in the natural history of heart failure, including the possibility of sudden death (6.1.4)
- encourage a positive but realistic approach to treatment and care
- promote patient and family/carer participation in decision making
- discuss advanced care planning and foster achievable goals of care (6.1.2)
- discuss any personal, social or spiritual issues raised by patients and carers (6.3).

'Good communication involves determining how much the patient wants to participate in decision making and tailoring information to what the patient wants to know at any given time. It identifies the patients' main problems, their perception of these and the physical, emotional and social impact on them and their family'³⁸.

It is particularly important that this ongoing and wide-ranging process of communication takes place between patients with heart failure and members of their health care teams²⁹. Experience is needed, however, to judge which patients want particular information and when³⁹. Patients with advanced heart failure may have a degree of cognitive impairment, due to various aetiologies, affecting their ability to understand and retain information. Including family members and other informal carers in discussions is important.

A desire to protect patients and families from potentially distressing information can make communication particularly difficult and complex⁴⁰. The enhanced communication approaches routinely used by palliative care teams are an essential tool to assist those caring for patients with advanced heart failure and their families in dealing with difficult issues and in providing appropriate support.

6.1.1 Breaking bad news

Clinicians need to provide information in a way that assists patients and their families to make appropriate decisions, to be informed to the level that they wish, and to cope with their situation. These skills can be enhanced through training, education, experience and support⁴¹. A number of useful approaches to breaking bad news and clinical practice guidelines for communicating prognosis and end of life issues have been published^{42,43,44,45}. A 'breaking bad news' website has also been established which, although relating largely to cancer, may also be helpful (see Appendix 4).

6.1.2 Advance care planning

Advance care planning is a process of documented and regularly reviewed discussion between a patient/family and their care providers about agreed goals and priorities of care including preferences for types and location of care. Its role in the care of those nearing the end of life has been recently emphasised^{45,46,47,48} (see also Appendix 2).

Discussions and decisions should be:

- clearly documented
- regularly reviewed
- routinely communicated to all those involved in the patient's care.

Advanced care planning should be discussed with patients and between health care teams soon after the onset of advanced heart failure or earlier if hospitalisation has occurred. The following points should be borne in mind:

- patient and carer preferences should be followed wherever possible
- some patients may choose not to express preferences

- some patients may not be in a position to do so because of cognitive impairment
- patient and carer preferences may change as circumstances alter, and should be frequently reviewed.

6.1.3 Advance decisions (living wills)

A competent patient has a legal right to refuse all treatment even if to do so hastens his/her death⁴⁹. An advance decision (also known as an advanced directive, an advance decision to refuse treatment, an advance statement or a living will) is usually a signed, written statement made by a competent person (ie one who has the necessary mental capacity) detailing how they wish to be treated at a future date should they be unable to express their wishes at that time. Oral statements made by the patient are also recognised. Advance decisions may be used to refuse treatment but not to request it.

Unlike the situation in England and Wales, enforcement of advance decisions is not covered by statute in Scotland. However, health care teams are obliged to take account of 'the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication'⁵⁰ and it is likely that courts in Scotland would take a similar approach to those in England⁵¹. Healthcare teams should decide whether the advance decision is a valid expression of the patient's wishes free of coercion, and whether it is applicable to the particular situation and to the particular decision that requires to be made. The issue of competence is dealt with by The Adults with Incapacity (Scotland) Act (2000) (see Appendix 4).

Advance decisions do not require to be prepared by a lawyer. They may take the form of a signed statement prepared by the patient him/herself, a completed proforma, a written entry in the case notes or a verbal expression of the patient's wishes. An occasion when the topic of dying is being discussed might be an appropriate time to enquire if a written statement exists or if information about this is wanted. The wearing of a Medic Alert emblem may be useful to advise the health care team of the existence and location of a patient's advance decision (see Appendix 4). It is recommended that copies are lodged with family members, the local acute hospitals, the GP and primary care team, with out of hours providers and with NHS 24.

6.1.4 Sudden cardiac death

40%-50% of patients with heart failure die suddenly and unexpectedly, usually as a result either of an arrhythmia or an acute coronary ischaemic event. Communicating this possibility sensitively to patients and their families can be challenging for health professionals in terms both of timing and of 'finding the words', and both experience and enhanced communication skills are required. However, since sudden death is most likely to occur during the earlier stages of the disease⁵², an appropriate opportunity to raise and discuss the issue should where possible be identified soon after diagnosis to allow patients and carers to prepare themselves for this eventuality. Where use of an implantable cardioverter defibrillator is appropriate, this may more easily provide such an opportunity with some patients.

6.1.5 Cardiopulmonary resuscitation (CPR) and Do Not Attempt Resuscitation (DNAR) orders

Increasing awareness of the rights of patients to express their wishes and of the implications of the concept of informed consent has led to updating of advice on this subject from professional organisations and statutory bodies. The approach to CPR and to DNAR orders should always be based on this advice and on current legal obligations. Key points include the following:

- there is a legally recognised duty to apply good medical practice in the best interests of patients: patients should be offered treatments which will improve outcomes such as prognosis and/or symptom control or quality of life
- there is no legal requirement to offer a treatment which is unlikely to be effective or which is likely to cause harm⁵³.

These points are particularly relevant in the case of patients with advanced heart failure, where it is generally believed that CPR will be unsuccessful and that those in whom it is initially successful are unlikely to survive to discharge^{54,55}.

Other current relevant guidance on this issue advises that:

- all members of the care team should be involved in the decision taken regarding CPR⁵⁶

- the decision and how it was made should always be documented^{49,56}
- the senior clinician (who may be a suitably experienced nurse) or GP in charge of the patient's care is responsible for the decision taken^{49,56}
- communication with the family and with the patient if competent is important in deciding whether CPR should be attempted⁴⁹.

An opportunity should be sought to discuss this issue with patients and families and reassurance given that other aspects of care would not be affected. To ensure that carers are not left feeling that they are responsible for making the decision, and to avoid the possibility of a future grieving process complicated by guilt, it should be emphasised that any acceptance of a DNAR decision is based on the firm advice of the health care team.

It should be noted that if a patient has a cardiac arrest at home and the family dials 999, the ambulance crew's guidelines may, if there is no advance care plan or DNAR form, require them to attempt resuscitation. The police may also be called to investigate a sudden death.

6.1.6 Deactivation of implantable cardioverter defibrillators (ICDs)

ICDs reduce the incidence of sudden death by up to 50%^{57,58} and are being implanted in an increasing number of patients with heart failure. If still functioning at the time of death, the device will continue to deliver shocks to the patient. This will be visible to family or friends who are present and is likely to cause them distress. This eventuality can be pre-empted, after discussing the issue with the patient and/or a carer, by requesting a member of the cardiac department to deactivate the device. Guidance on management of ICDs is included on the Liverpool Care Pathway for the Dying Patient website (see Appendix 4) and detailed guidance on deactivation of ICDs has been published by the British Heart Foundation⁵⁹.

Bereaved relatives / carers should be made aware that ICDs must be deactivated and removed prior to cremation.

6.2 Symptom management

The distressing symptoms experienced by many patients with advanced heart failure often remain untreated for one of three reasons:

- they are not identified or addressed by the health care team²¹
- patients do not mention them⁶⁰
- the symptoms are resistant to conventional treatment²².

Many of these symptoms are caused not by heart failure^{21,30} but by co-morbidities, the side effects of drugs or by the psychological and practical consequences of disease progression.

Effective symptom control can be achieved by using generic skills and the expertise and treatment protocols developed originally in the palliative care of patients with cancer. Appendix 1 highlights some common symptoms and the special considerations appropriate when applying the principles and practice of palliative care to patients with advanced heart failure.

6.2.1 A palliative care approach to symptom management

Treatment options should be discussed openly with patients and their families and their preferences taken into account when reviewing their medication and management. Some patients will want to continue all treatment that might extend their lives. Others find complex drugs regimens burdensome and want these simplified. When patients experience difficulty in taking their medication or when concordance with prescribed medication seems to be poor, a compliance needs assessment undertaken by a pharmacist may be beneficial.

Any treatment plan should be clearly documented and communicated to the patient and family and to all health care teams involved. The plan should include the indication for each medication currently prescribed, the reasons for each recommended drug change or discontinuation and a plan for monitoring and reviewing the regimen. Drugs that have been appropriate and/or well tolerated earlier in the course of the illness may no longer be appropriate.

6.2.2 Symptom control when patients can no longer tolerate oral medication

A syringe driver or pump can be used in the management of symptoms including pain, anxiety and nausea. The subcutaneous route is preferable to the intravenous route as less medical intervention is needed and it can be used in the community. The drugs used in a syringe driver are known to be well absorbed from the skin with minimal irritation. It should be noted, however, that drugs administered subcutaneously may be poorly absorbed as a result of oedema, and subcutaneous infusions should be used on the upper part of the body to avoid areas of gross oedema. The principles of the use of opioids, antiemetics and benzodiazepines are similar to those outlined in the appropriate sections of Appendix 1. Detailed information on drug combinations and doses in subcutaneous infusions can be obtained from local palliative care guidelines or by consultation with local palliative care specialists, or from the current edition of the *Palliative Care Formulary*⁶¹.

6.3 Psychosocial and spiritual care

The social, psychological and spiritual impact of the late stages of heart failure can be as detrimental to quality of life as the physical symptoms. There is evidence that such aspects are often overlooked, however: patients with advanced heart failure have less in the way of practical help, financial benefits, social services and counselling support than those with other chronic conditions^{29,62} and patients and families would benefit from improved psychosocial care⁶³.

In order to improve the care and support offered to patients and carers, health professionals should be able to recognise unmet needs that are causing significant distress and refer appropriately to providers of social, psychological or spiritual care^{64,65}. Specialist palliative care support should be sought for patients who have complex psychosocial needs, whether or not they also have complex physical needs⁶⁶.

The physical and psychological impact on family members of caring for someone with advanced heart failure should not be underestimated, and carers should be advised of their right (under the Community Care and Health (Scotland) Act 2002) to an assessment of their own holistic needs and directed to local carer support organisations where these are available (see Appendix 4). Patient support organisations also provide a range of information and services (see Appendix 4).

6.3.1 Psychological issues

People with advanced heart failure may experience a range of psychological and emotional difficulties which affect attitudes, relationships, behaviour and quality of life. Fear, anger and depression are a reaction to the situation in which patients find themselves. Denial may be a part of someone's coping strategy.

Unaddressed existential, philosophical or spiritual issues (see 6.3.5) may also be a cause of fear and anxiety. Loss of physical independence and a feeling of being a burden are common issues. Younger patients with heart failure may experience greater difficulty in adjusting to or accepting the progressive physical and emotional losses of function, status, income, roles and relationships which are part of the reality of living with the condition.

To address such needs sensitively, it is important to recognise and acknowledge the patient's emotions as part of the ongoing therapeutic dialogue⁶⁷. This process of identifying and exploring issues of concern to the patient and carers should begin early in the course of the disease and continue, with additional support as required, as symptoms progress.

6.3.2 Information needs

Provision of information is an important part of the proactive care of patients and carers⁶⁶. Information about diagnosis and prognosis allows for plans to be made and protects against futile treatment⁶⁸, while lack of information has been shown to contribute to high rates of depression³⁹.

Oral communication skills (see 6.1) are an important factor in the provision of timely and appropriate information, as is the availability of accurate, locally relevant, written information (see the *Information Support Checklist, Appendix 3 of Joined up thinking ... Joined up care*⁶⁶). National charities such as British Heart Foundation Scotland and Chest, Heart & Stroke Scotland, as well as national and local carer support

organisations such as the Princess Royal Trust for Carers, are valuable sources of information (see Appendix 4). NHS Boards are required to have a strategy which meets the information needs of patients, relatives and carers.

6.3.3 Social needs

Many patients with advanced heart failure become housebound and a number require assistance with basic personal and household tasks. Needs may include:

- personal and domestic care (washing, dressing, meals, housework, shopping etc)
- access to aids and adaptations (disability aids, shower, wheelchair, ramp, commode etc)
- access to respite and day care
- practical and emotional support for carers.

Access to the relevant social services can be inconsistent and fragmented and is often not sought or provided for heart failure patients. A key health care worker could coordinate support needed for individual patients from the different provider services available⁶⁶. This may involve a combination of health, social work and voluntary sector services, including the provision of support for carers (see Appendix 4).

6.3.4 Financial issues

There is evidence that patients with progressive diseases are frequently concerned about their ability to cope financially and about the impact that this has on their families^{69,70,71}. Health care professionals supporting patients with advanced heart failure should therefore be aware of actual or potential financial hardship as a source of stress and practical difficulty and should be able to signpost patients and carers to local welfare benefits advice organisations.

They should also be aware of the 'special rules' (DS1500) application procedure for access to Disability Living Allowance and Attendance Allowance for patients who are suffering from a progressive disease and who might reasonably be expected to die within six months. This form of financial support can significantly ease hardship and stress in the last months of life but is currently underused for patients with advanced heart failure⁷².

6.3.5 Spiritual needs

Recognising that people have spiritual needs is an important aspect of psychosocial care, and unmet spiritual need is a further cause of distress among people with heart failure and their carers⁷³. 'Spirituality' refers to whatever gives a person meaning, value or worth in his or her life. It includes religious practices and beliefs but equally, other aspects of life which are important to the individual such as family and other personal relationships, music, art, poetry or a love of nature. Any support which can be given to the patient in accessing whatever is important to him/her may be helpful.

Many patients seek a meaning and purpose in their experience as an expression of their spiritual needs. The distress caused by the inability to find answers to questions such as 'why me?' or 'why now?' may remain unacknowledged and unaddressed, with patients feeling unable to express such concerns to clinicians, and clinicians reticent to raise such sensitive issues themselves due to lack of time, a feeling that they should wait for a cue, or a feeling of being unprepared or unskilled⁷⁴. Spiritual support may be provided, however, by being willing to engage in dialogue or simply by 'being there' and acknowledging the person's concerns. Often anxiety can be relieved simply by expressing fears and concerns, being listened to and having such issues and feelings acknowledged.

Health care professionals who feel personally unable to address these issues should recognise this and suggest a colleague or an appropriate religious or non religious advisor or counsellor who can do so. For many patients and their family and friends, comfort and peace of mind come from a religious faith. All NHS Boards are required to provide a chaplaincy service to ensure that the spiritual needs of all patients, including those from ethnic minority groups who wish to pursue specific cultural and religious practices, are met⁷⁵.

Training in spiritual care is recommended as being 'a normal part of professional development for all clinical

and non-clinical staff involved in patient care throughout the NHS⁷⁵. Training resources for spiritual care are also available (see Appendix 4).

6.4 Terminal care

When the health care team has reached agreement that a patient has entered the dying phase of their illness (3.7) this conclusion and its implications should normally be discussed with the patient if appropriate, and with their family or carers. Issues which need to be raised may include:

- discontinuation of active treatment (6.4.1)
- advance decisions and preferred place of care (6.1.3, 6.4.3, 7.3)
- implementation of an integrated care pathway (6.4.2)
- do not attempt resuscitation directives (6.1.5)
- deactivation of an ICD (6.1.6)
- religious preferences and rituals (6.3.5).

Close collaboration between patients, their carers and health care professionals under whose care the patient is when they become terminally ill, is essential in planning the patient's management throughout this stage to ensure their optimum medical care and support. It is important that patients and family/friends should not be left with the impression that 'nothing else can be done' but that every effort will be made to ensure symptom relief and psychological and spiritual support.

6.4.1 Discontinuation of active treatment

It should be explained that most conventional treatment will be withdrawn, medical tests will not be undertaken and intravenous lines taken down. Patients and carers should be assured, however, that:

- withdrawal of conventional treatment does not mean withdrawal of care
- discontinuation of conventional medications does not mean that treatment will cease
- control of physical and psychological distress is now the overriding priority of the care team
- the care which is being suggested does not shorten the patient's life, nor does it constitute euthanasia or assisted suicide.

In discussions with patients and families the emphasis should be on what will be provided rather than on what will be discontinued. The implementation of end of life / terminal care thus means that any treatment which is not contributing significantly to symptom control should be withdrawn and additional palliative measures introduced as appropriate. If swallowing is becoming difficult any necessary medication should usually be given subcutaneously.

6.4.2 Implementation of an integrated care pathway

The use of an end of life care strategy, such as the Liverpool Integrated Care Pathway for the Dying Patient (LCP) (see Appendix 4), and its benefits in providing the patient with optimum care for any physical or psychological distress occurring during the dying process, should be discussed with the patient and their carers. The LCP is:

- a multi-professional generic document detailing all aspects of intervention and care for the dying patient
- designed to replace all other documentation
- applicable in hospital, hospice, care home and community settings.

The LCP is a valuable tool for the non-specialist and helps to facilitate:

- effective communication within the multi-disciplinary team and with the patient and family
- anticipatory planning including psychosocial and spiritual care
- anticipatory prescribing for symptom management
- appropriate bereavement care.

The Scottish Partnership for Palliative Care has recommended support for flexible use of the LCP as part of a cohesive approach to palliative and end of life care across Scotland⁴⁶. It is also recommended for patients with advanced heart failure by the NHS Modernisation Agency⁶.

It is customary for the LCP to be initiated only in the last few days of life but it is important to accept that patients may improve after they are commenced on the pathway. There are several possible explanations:

- improvement may reflect the effect of good basic care
- improvement may be because medications which were causing unrecognised side effects have been stopped
- the diagnosis of terminal heart failure may have been incorrect.

None of these constitutes failure on the part of the care team. The patient can be taken off the pathway, which can be re-instituted at a future date as necessary.

6.4.3 Preferred place of care

If a patient chooses to move from hospital to home during the terminal stage the hospital health care team should ensure, by liaising with the primary care team before the patient is moved, that the agreed health and social care package, including provision of end of life medication, is in place.

7. Delivering more effective services for people with advanced heart failure

7.1 Continuity and co-ordination of care

Co-ordination of the care of patients with advanced heart failure becomes increasingly complex as the disease progresses and there is a real risk of care becoming fragmented because of the increased numbers of healthcare professionals involved⁷⁶. Most people with heart failure spend the majority of their last year at home, cared for by their primary care team⁷⁷. The primary care team should be able to access support when needed from a cardiologist, specialist heart failure nurse services and specialist palliative care services. At various times other professionals such as social workers, pharmacists or psychologists may be involved. Patients who are repeatedly hospitalised are often placed in the care of different consultant teams, including those of general medicine and medicine for the elderly.

Effective communication and collaboration between care teams and organisations is thus essential for the effective delivery of services³⁶. Poor communication between primary and secondary sectors is a common concern, and any attempt to improve liaison and share information is likely to enhance care⁷⁸. Pilot models for shared care involving both cardiological and palliative care services have recently been developed and evaluated⁴⁰, and the need for improved joint working between health and social care has also been highlighted⁴⁶.

Improved communication and collaboration across all sectors should:

- minimise confusion and 'mixed' or contradictory messages for patients and carers
- ensure a shared management strategy
- speed up access to services
- ensure clear dissemination of information to all professionals involved across organisational boundaries including the transfer of information to NHS 24 and those providing out of hours care.

A key individual in the health care team should be identified to co-ordinate and provide continuity of care and to liaise with colleagues^{77,78}. Where heart failure is the dominant problem, this may either be a heart failure specialist nurse working with the primary care team or a designated and suitably trained member of the primary care team, liaising as appropriate with heart failure services. For patients whose heart failure is not the dominant concern, the co-ordinating role could be carried out by a community nurse or general practitioner.

7.2 Supporting patients in the community

Patients with advanced heart failure may be supported in the community through a variety of existing mechanisms. Heart failure specialist nurses (7.2.1) can play a key role in co-ordinating post-discharge and follow-up care⁸ and enabling patients to remain in, or return to, the community. The Gold Standards Framework (7.2.2) is used by some primary care teams providing planned and anticipatory care for patients with advanced heart failure. The new General Medical Services contract promotes proactive management specifically for patients with heart failure with the introduction of practice registers and regular patient reviews (See Appendix 4), while interim results of a joint initiative involving district nurses, heart failure specialist nurses and Marie Curie nurses⁷⁹ indicate a reduction in heart failure related deaths in hospital and improved quality of life for patients and carers and suggest that care and support could be further enhanced by improved access to:

- rapid response acute care
- day and night respite care
- intravenous diuretics in the community (see also 7.3).

7.2.1 The role of the heart failure specialist nurse

For patients with advanced heart failure, heart failure specialist nurses can fulfil the crucial role of co-ordinating care and can provide patients and carers with psychological and educational support. All are experienced in adjusting medication and many are now able to prescribe. They provide a link between

primary and secondary sectors, and liaise with other health and social care professionals⁸⁰. Their role includes:

- early identification of patients with advanced heart failure
- comprehensive assessment, in collaboration with other key health professionals, to determine the role of active treatment and a supportive care approach in the management of individual patients
- ensuring that patient documentation and future management plans are readily available across primary, secondary and tertiary sectors
- facilitating the access of patients to hospital wards for those requiring admission
- establishing closer collaboration between cardiac, palliative care and community staff⁸¹.

There are currently 60 heart failure specialist nurses (46.7 WTE) across Scotland.

Patients for whom such specialist nurses are not available due to reasons of geography or eligibility criteria can be appropriately supported in the community through the identification of a key individual to co-ordinate their care and provide support (see 7.1)

7.2.2 Gold Standards Framework (GSF)

The GSF⁸² is a generic framework of strategies, tasks and enabling tools designed to help primary care teams to improve the organisation and quality of care for patients during the last 12 months of life, whether at home, in community hospitals or in care homes. It is based on three main principles:

- the identification of patients in need of palliative / supportive care towards the end of life
- assessing patients symptoms, preferences and any other issues important to them
- planning care which prioritises patients' needs and preferences, in particular allowing people to live and die where they choose.

The framework encourages:

- anticipatory care
- the development of multidisciplinary working across sectors and between health care teams
- improved communication between individuals, teams, patients and carers to
- increased patient involvement in decision making
- the introduction of a strategy to ensure integrated 24 hour care when needed.

The Gold Standards Framework (GSF) was one of the tools recommended in the Department of Health NHS End of Life Care Programme in England (December 2004 – March 2008)⁴⁵. An adapted version of the GSF is widely, but not universally, used in Scotland as a result of the three-year Gold Standards Framework Scotland (GSFS) project (October 2003 – October 2006)⁸³. Community Health Partnerships (CHPs) have been instructed to take account of the framework⁸⁴ and adoption of its principles has been recommended to all general practices in Scotland⁴⁶. It is particularly appropriate for use in the management of patients with advanced heart failure, and has been recommended to general practices as part of a three-step approach⁷⁷.

7.3 Decisions regarding hospitalisation

Patients with advanced heart failure are often hospitalised because of worsening symptoms. This may be clinically appropriate and in keeping with the wishes of the patient and carers. It may be unnecessary, however, if nothing is to be gained in terms of symptom relief or improved quality of life.

Factors which suggest that hospitalisation is appropriate might include:

- unidentified cause of current deterioration
- the opportunity to treat effectively a cause of deterioration which cannot be diagnosed or treated at home (such as a chest infection, acute cardiac pain or recent onset of atrial fibrillation), with a realistic prospect of the patient being discharged in an improved physical state and/or with a better quality of life
- the need for intensive diuretic therapy if this cannot be delivered or monitored in the community (see also 7.2)
- patient/carer distress and/or inability of carer to cope at home.

Despite these possibilities, if the patient is actually in the process of dying and has previously (or currently)

expressed a wish to remain at home then if possible this request should be fulfilled.

Factors suggesting that hospitalisation is not appropriate would include the following:

- the patient does not wish to be hospitalised
- recent hospitalisation to treat deteriorating cardiac function produced neither objective nor subjective improvement
- the patient is unsuitable, or does not wish to be considered, for interventional treatment such as inotrope therapy or cardiac surgery.

Decisions regarding hospitalisation should always be explained and discussed fully with patients and families so that they can exercise informed choice.

7.4 Overcoming barriers to delivering more effective services

Barriers and challenges to delivering more effective services for people with advanced heart failure remain^{36,77,78} and include:

- lack of knowledge about heart failure compared to cancer care
- lack of general palliative care expertise and advanced communication skills
- misperceptions of patients, carers and professionals about the role of palliative care
- prognostic uncertainty leading to failure to identify patients with advanced heart failure in need of a palliative care approach
- lack of carer support including day time respite and night care
- lack of time and resources to organise appropriate services.

It is clear that investment in additional and/or reconfigured services as well as investment in education and training will be among the measures required to address these barriers, as will the increased sharing of knowledge and expertise and the establishment of ongoing communication mechanisms among the various professionals involved.

7.5 Education, training and sharing expertise

Enhanced communication and the sharing of education and skills between health care teams can help to create a successful model of integrated care for patients with heart failure⁸⁵. The provision of joint educational opportunities among specialists in palliative care and cardiac care and generalists in primary care to share information and awareness about heart failure and palliative care would also be likely to enhance care⁴⁰. To be fully effective, such joint initiatives should also involve secondary care teams in general medicine and medicine for the elderly. Health professionals in general also need a raised awareness of social problems and better knowledge of local services and support groups.

Steps should be taken, therefore, to identify the educational needs of all professional groups involved in the care of patients with heart failure, and access to appropriate formal and informal multi-professional training opportunities should be facilitated. Where such education and training programmes and opportunities do not yet exist they should be developed locally, and/or nationally as appropriate. Reciprocal opportunities to share knowledge and experience and to gain an understanding of the management of patients with advanced heart failure should be available among all health and social care teams involved.

7.5.1 General palliative care skills

The NHS Modernisation Agency has recommended that health care professionals involved in the management of heart failure patients should aim to acquire the necessary skills and knowledge to provide basic palliative care⁶.

Education and training opportunities in general palliative care are provided routinely across Scotland by specialist palliative care units and voluntary hospices as well as by various academic departments and other organisations (See Appendix 4, Palliative care education). The NHS provides education in-house in collaboration with higher education institutions, and local and regional palliative care Managed Clinical Networks may also be able to provide both formal and informal education and training opportunities.

7.5.2 Enhanced communication skills

The General Medical Council (GMC) and other professional bodies including the Royal College of Physicians and the Royal College of General Practitioners have stressed the importance of doctors developing good communication skills⁸⁶. The particular complexity of communication in heart failure and the need for improved communication skills on the part of those caring for patients with heart failure has been recognised^{40,87}, while NICE (2004) recommends enhanced communication skills training for all those who are required to communicate complex or distressing information.

The experience gained from communication training initiatives developed for cancer professionals may be useful⁸⁸, and all professionals caring for people with advanced heart failure should have access to advanced clinical communication education programmes that use proven experiential teaching and learning methods.

7.6 Future research needs

This report has confirmed the need for further research to evaluate different models of care provision for people with advanced heart failure and to determine which interventions best improve quality of life^{8,89}. Further research on symptom control in advanced heart failure to facilitate the development of further guidance would also be useful. A research focus on the need for a flexible, multi-dimensional framework of services for people with advanced heart failure, rather than a single model, has recently been suggested⁷⁷.

8. Conclusions and recommendations

Much has been done in recent years, in the UK and elsewhere, to raise awareness of the need of patients with advanced heart failure for a holistic and palliative approach to care, encompassing physical, psychological, social and spiritual needs. This report emphasises the need for such an approach to be adopted by the members of all health care teams involved, to be phased in sensitively and as appropriate from the time of diagnosis onwards, and to be based on open and honest communication regarding diagnosis, prognosis, and the inherent uncertainty, including the possibility of sudden death, of the disease trajectory.

It is thought that the required combination of active and palliative care will be best achieved by a model of shared care and enhanced communication involving multi-professional teams across cardiology, primary care, specialist palliative care, general medicine, medicine for the elderly and social care. Care should be co-ordinated by a named individual such as a heart failure specialist nurse or other suitably trained health professional. Efforts to introduce appropriate models of service provision will be enhanced by the creation of reciprocal opportunities, ideally but not exclusively through cardiac and palliative care Managed Clinical Networks, for shared dialogue and multi-professional education for staff at all levels. This should encompass:

- the principles and practice of general palliative care
- characteristics of the heart failure trajectory
- key factors in clinical management of patients with advanced heart failure.

It is unlikely that the models and standards of care envisaged can be delivered without investment in some level of additional resources in addition to re-organisation of existing services. The provision of appropriate levels of trained staff to meet the needs of patients and families for support and for continuity and co-ordination of care should be considered in future workforce planning, and further palliative care research should be undertaken to identify the most effective models of care.

The report's conclusions are reflected in the following recommendations:

RECOMMENDATION 1

All patients with advanced heart failure should be provided with both optimum cardiological management and palliative care.

- 1.1 All patients with advanced heart failure should be proactively identified and placed on the primary care supportive and palliative care register.
- 1.2 All patients with advanced heart failure should be actively monitored by the primary care team and assessed to see if additional advice, assessment or care from the specialist heart failure nursing service and/or local palliative care service is appropriate.
- 1.3 Primary and secondary care teams should have access to cardiological and specialist palliative care expertise and advice when required.

RECOMMENDATION 2

Health care teams should adopt a holistic approach to the care of patients with heart failure, ensuring not only optimum management of physical symptoms, including those relating to co-morbidities, but also identifying and addressing practical, social, psychological, emotional and spiritual needs.

- 2.1 Members of health care teams should be aware of the range of physical symptoms such as breathlessness, nausea and pain, and of the effects of complex multiple drug regimes, likely to be experienced by patients with advanced heart failure. They should address these proactively and with palliative care support where necessary.
- 2.2 The needs of people with heart failure and their carers for clinical, practical and financial information should be recognised and appropriate written information provided at local level.

Health care professionals should be aware of actual or potential financial hardship as a source of stress and practical difficulty for patients and families and should be able to signpost patients to local welfare benefits advice organisations. All patients with advanced heart failure should be considered by their doctors for a 'special rules' (DS1500) benefits application.

- 2.3 Members of the health care team should be aware of the multi-agency services available locally, including social work services and the voluntary sector, and where necessary signpost/arrange access to the support required.
- 2.4 Health care professionals should explore the wishes of patients to engage in dialogue about emotional and spiritual concerns. Appropriate specialist support should be identified and offered where required.

RECOMMENDATION 3

Members of health care teams should ensure that patients with advanced heart failure and their carers have sufficient opportunities to discuss, at their own pace and at times of their choosing, any issues that are important to them, including the management of the condition and its prognosis.

- 3.1 A continuing dialogue of open, sensitive and honest communication appropriate to the patient's wishes and needs should be initiated at the time of diagnosis and maintained throughout all stages of the disease trajectory.
- 3.2 All patients with advanced heart failure and their carers should have the opportunity to discuss and make documented decisions regarding their priorities and preferences for end of life care. Goals of care should be discussed openly with the patient and family.
- 3.3 Prognostic uncertainty should be accepted by clinicians, sensitively communicated to patients and families, and incorporated into a process of joint decision-making and forward planning.
- 3.4 The possibility of sudden death should be acknowledged by clinicians as an unpredictable but recognised feature of the heart failure trajectory and the possibility of its occurrence (and where appropriate of preventative strategies) communicated sensitively to patients and carers.

RECOMMENDATION 4

A model of shared care involving close collaboration between different healthcare teams should be implemented in the care of patients with advanced heart failure.

- 4.1 Patients should remain in the care of their primary care team and of a single hospital care team throughout the course of the patient journey, with specialist advice and support from a cardiologist, palliative care specialist and others as required.
- 4.2 A key individual should be identified to co-ordinate care management and to liaise between the patient, family and other healthcare professionals.
- 4.3 There should be a management plan that involves key members of all relevant care teams in decision-making processes.
- 4.4 Referral protocols for accessing specialist cardiological and palliative care advice and consultation should be in place for patients with complex needs.
- 4.5 Steps should be taken to improve the sharing of information within and between healthcare teams.
- 4.6 Patients and carers should be provided with the appropriate telephone contact numbers and know whom to contact for out of hours care.
- 4.7 NHS 24 and out of hours providers should be aware of the identity of patients with advanced heart failure and know how to respond to any calls.

RECOMMENDATION 5

Arrangements for appropriate end of life care should be in place for all patients with advanced heart failure.

- 5.1 Established tools for end of life care, such as the Gold Standards Framework for co-ordinating the care of patients with advanced heart failure and the Liverpool Integrated Care Pathway for managing the last few days or hours of life, should be implemented.
- 5.2 Mechanisms should be in place for the safe cessation of unnecessary medication and implantable devices.
- 5.3 Arrangements for anticipatory prescribing should be in place, particularly before weekends, as a proactive response to any anticipated worsening of symptoms.

RECOMMENDATION 6

Educational and training opportunities should be provided for all health and social care professionals caring for people with heart failure to enable them to understand the patient's cardiological problems and to address their general palliative care needs.

- 6.1 Reciprocal opportunities to share knowledge and experience and to gain an understanding of the management of patients with advanced heart failure should be available among all health and social care teams involved.
- 6.2 Members of primary care, social care and hospital ward teams who care for heart failure patients should be assisted by their cardiac and palliative care MCNs to access multi-professional training opportunities to develop basic palliative care skills.
- 6.3 Members of specialist palliative care and primary care teams who care for heart failure patients should be assisted by their cardiac and palliative care MCNs to access multi-professional training opportunities to enhance their knowledge and awareness of the clinical needs and cardiological management of such patients.
- 6.4 Advanced clinical communication education programmes using proven experiential teaching and learning methods should be available in all NHS Board areas. Health professionals caring for people with heart failure and their families should attend such training if they have not already done so.
- 6.5 Training opportunities in spiritual care should be available in all NHS Board areas for all interested health professionals to enable them to identify and respond appropriately to the existential suffering and spiritual needs of their patients with advanced heart failure.

RECOMMENDATION 7

Further palliative care research should be undertaken in order to:

- examine the need for a flexible, multi-dimensional framework of service for people with advanced heart failure
- identify the most effective models of care
- determine which interventions best improve symptom control and quality of life.

RECOMMENDATION 8

The resource implications of this report and recommendations should be addressed:

- consideration should be given to reorganisation of existing services to meet increasing need and to support implementation of the above recommendations
- additional resources should be made available to both primary and secondary care to enable full implementation of the above recommendations.

Appendix 1 Symptom management and palliative care

This section is not intended as a comprehensive guide to symptom control. It highlights some common symptoms and the special considerations appropriate when applying the principles and practice of palliative care to patients with advanced heart failure. More detailed information can be obtained from local palliative care guidelines or by direct consultation with local specialist palliative care services.

Anxiety

Anxiety is common and understandable, and may result from lack of knowledge about the illness and its future course or fears about potential symptoms or life threatening complications. The initial approach should be to explore the patient's ideas, concerns and expectations and to encourage a full discussion. An explanation of the patient's physical condition and the cause of symptom(s) should be given. Any reassurance should be given in an honest but realistic manner and needs to address the patient's concerns, including ways in which the situation can be managed.

Anxiety, breathlessness and pain can all become interrelated. Coping and functional ability can be enhanced by anxiety management and controlled breathing techniques and by planning and pacing activities⁹⁰. Family carers need to be included in any anxiety management plan.

Medication

Some patients will require medication such as a benzodiazepine (or if they are confused, a neuroleptic such as haloperidol could be considered). If the anxiety is related to nocturnal breathlessness, a low dose of oral opioid (eg morphine 2mg - 5mg initially) may be used. Chronic anxiety may respond to regular low dose diazepam or, in those with a prognosis of more than a month, to an antidepressant such as sertraline or mirtazepine. Sedatives are recommended for management of anxiety and distress in dying patients and this medication may be given via a continuous subcutaneous infusion. Neither opioids nor haloperidol should be used in escalating doses for sedation.

Breathlessness (Dyspnoea)

Non-pharmacological measures are important, especially in the earlier stages of disease. Breathlessness can be helped by measures such as an electric fan, open window, positioning of the patient (eg sleeping upright when necessary), breathing techniques, exercises, activity pacing techniques and relaxation strategies.

Medication

Patients who are anxious and distressed because of episodes of breathlessness may benefit from a short acting benzodiazepine. Sublingual lorazepam (0.5mg -1mg lorazepam sublingual) can be used as required, or midazolam (2mg - 5mg) given by subcutaneous injection or via a syringe driver (5mg - 40mg). Subcutaneous injections are given in the outer part of the upper arm and drivers sited here or on the anterior chest wall as these areas are rarely affected by oedema. Titrated doses of a suitable opioid can improve dyspnoea. If the patient has significant renal impairment (as is the case in many patients with heart failure), cautious titration of immediate release morphine or of alternative opioids such as immediate release oxycodone, low dose fentanyl patches, or subcutaneous alfentanil is recommended⁹¹.

Depression

Depression is often overlooked but is a serious complication of heart failure, affecting between a third and half of patients⁹². A diagnosis of depression should be actively sought and discussed openly with the patient. Referral to a psychologist may be appropriate and cognitive behavioural therapy, where available, is an alternative approach to both anxiety and depression in advanced disease.

Medication

A selective serotonin receptor inhibitor (SSRI) or mirtazepine should be used. Tricyclic antidepressants, which may cause cardiac arrhythmias, should be avoided (SIGN 95 page 13 section 3.6). Paroxetine is not recommended because of a high incidence of acute withdrawal symptoms if it has to be discontinued quickly.

Gout

Gout is an important complication of diuretic therapy and usually presents as an acute monoarthritis. The onset is sudden with a painful, exquisitely tender, swollen, red and hot joint.

Medication

Little evidence is available in this area. SIGN 95 (page 19 section 4.11) indicates that current practice in the management of acute gout is to use colchicine to suppress pain and inflammation. Careful consideration or monitoring is required. An alternative is a short course of prednisolone. SIGN 95 also recommends that starting prophylactic antagonist therapy and stopping colchicine should be considered once the pain is under control.

Non-steroidals (NSAIDs) should be avoided because of potential fluid retention and possible renal toxicity.

Itch (Pruritis)

Itching is a common and distressing subjective symptom which may interfere significantly with the quality of a patient's life. Treatment is aimed at identifying and treating the underlying cause as well as securing symptomatic relief. Causes may include drug allergies or existing skin or systemic conditions. Symptomatic treatment is primarily aimed at keeping the skin moist and cool. Accurate assessment to determine the underlying cause is essential.

Medication

Emollients may relieve some but not all causes of itch. Antihistamines help some patients. There is anecdotal evidence that paracetamol may relieve symptoms in some patients.

Light-headedness

Light-headedness is usually caused by either persistent or postural hypotension. Some patients develop dizzy spells due to low blood pressure when a drug known to cause hypotension is introduced or the dosage of another drug is increased. This should be discussed with a member of the heart failure team. The medications most likely to cause postural hypotension are shown in Appendix 2.

Hypotension associated with drug peak effects may be reduced by adjusting the administration of heart failure medication by splitting or staggering doses. Educating the patient about avoiding sudden changes in position, especially from lying or sitting to standing, is an important part of management.

Muscle wasting and fatigue

Muscle-wasting and marked weight loss (cardiac cachexia), are complex multifactorial problems. Physiotherapy, occupational therapy and gentle exercise, if possible, are important in maintaining function. Assessment of the patient's diet and energy intake should be undertaken by a dietician. Beta-blockers can cause muscle fatigue so should be reviewed.

Nausea and vomiting

The appropriate treatment depends on the aetiology. Medication should always be reviewed and any causative drugs changed or reduced if possible. Taste or smell of oral liquid medicines may be a contributory factor. Constipation should always be excluded as a cause. Non-pharmaceutical approaches to nausea include offering frequent small meals and following the patient's food preferences.

Medication

If delayed gastric emptying secondary to hepatic congestion is the cause of nausea this can be treated with a prokinetic such as metoclopramide (or domperidone if needed longer term).

Haloperidol may be considered for control of chemical nausea due to medication or organ failure but cannot be used long term due to a high incidence of extra-pyramidal side effects.

Levomepromazine (3mg - 6mg / day orally) is a broad spectrum antiemetic widely used by palliative care services when other antiemetics are ineffective; it is rarely used first line. It is a potent cause of hypotension in those with cardiac failure and must be used in carefully titrated low doses. As

levomepromazine has a long half life and can cause sedation it is best taken at night. The smaller 6mg tablets are an unlicensed preparation available on a named patient basis.

Steroids should be avoided in heart failure as they can contribute significantly to fluid retention.

Oedema

This is a very distressing symptom and its relief can raise morale as well as helping patients' mobility. Progress can be assessed by regular monitoring of weight. A slow and steady diuresis with a target weight loss of around 0.5kg - 1kg per day is preferable to an acute loss of fluid.

Medication

Furosemide remains the first line diuretic. If the oedema is resistant, additional diuretics such as bendroflumethiazide or metolazone may be considered under specialist supervision. Patients receiving additional diuretics need additional electrolyte monitoring and failure to respond to oral treatment may suggest that hospital admission is appropriate (see 7.3).

Pain

50% of patients dying from heart failure have distressing pain, the aetiology of which is often unclear⁹³.

Medication

Opioids can be effective for persistent cardiac pain unresponsive to anti-anginals. This should be approached using the WHO analgesic ladder starting with regular paracetamol and progressing to an appropriate opioid. NSAIDs should be avoided in heart failure due to their fluid retaining properties (SIGN guideline 95).

Pain can also be caused by gastro-intestinal congestion, immobility and gross oedema. These pains will also respond to low dose titrated opioids. Opioids with renally excreted, active metabolites (codeine, morphine, diamorphine, oxycodone and hydromorphone) should be used with caution in patients who have stage 4-5 chronic kidney disease (eGFR <30ml/min) as they will accumulate and cause toxicity if repeated doses are given. If oral opioids are used in patients with poor or deteriorating renal function, immediate release formulations should be used in preference to modified release preparations to reduce risk of toxicity and to facilitate prompt dose adjustment.

Alternative opioid formulations which can be administered by different routes and are generally used for cancer patients (such as fentanyl by patch, buprenorphine administered sublingually or alfentanil, a potent, short acting opioid, as an injection), may be appropriate in providing effective pain relief. Patch formulations are slower to take effect and so will be of less use for immediate pain relief. Injection preparations can be given subcutaneously or sublingually, or for maintenance as a subcutaneous infusion in a syringe driver. Advice should be sought from local palliative care specialists.

Tricyclic antidepressants as analgesics are not recommended as they may cause arrhythmias (see SIGN guideline 95).

Renal impairment

Renal impairment and heart failure are closely interrelated:

- the prevalence of both increases with age
- each can cause and worsen the other
- ACE inhibitors, angiotensin receptor blockers and diuretics may worsen renal impairment
- eGFR, which is now routinely reported, provides a better measure of renal function than serum creatinine
- NSAIDs may cause or worsen renal impairment (See SIGN 95 appendix 1).

The optimum treatment for heart failure depends on finding a balance between achieving the recommended doses of cardiac medication and avoiding unacceptable deterioration in renal function.

Appendix 2 Examples of approach to reassessment of medication in advanced heart failure

Drug	Survival improved	Symptom control improved	Side effects*	Assessment / review
ACE inhibitor (angiotensin converting enzyme inhibitors)	yes	yes: less dyspnoea/ fatigue; improves functional capacity; can reduce hospital admissions	cough, hypotension, lightheadedness, hyperkalaemia, renal impairment	Stop during any intercurrent illness which causes hypovolaemia. Caution if renal impairment or on other potassium conserving medication. Should ideally be reviewed by heart failure team.
Amiodarone	no	yes: by lessening dysrhythmias especially AF	hepatic dysfunction, photosensitivity, thyroid dysfunction, nausea. Important adverse interaction with other drugs which prolong the QT interval	Effective drug, but significant risk of adversely affecting quality of life. Very long duration of action. May take weeks-months for effect to be lost after discontinuation.
ARB (angiotensin receptor blockers)	yes	yes: as for ACE inhibitor	hypotension, lightheadedness, hyperkalaemia, worsening renal function	Stop during any intercurrent illness which causes hypovolaemia. Caution if renal impairment or on other potassium conserving medication. Should ideally be reviewed by heart failure team.
Aspirin	yes	no	GI irritation/haemorrhage	Stop if causing any symptoms. No proven role in non-ischaemic heart failure.
B Blocker	yes	yes: as for ACE inhibitor	fatigue/muscle weakness, nightmares, depression, cold peripheries	Stop or reduce dose if worsening dyspnoea or fatigue. Avoid abrupt withdrawal if possible.
Digoxin	no	yes: as for ACE inhibitor	nausea, vomiting, bradycardia/heart block, bigeminy	Risk of toxicity (e.g. in renal impairment) hence monitor levels. Risk of significant drug interactions. (see Appendix 1 BNF).

Drug	Survival improved	Symptom control improved	Side effects*	Assessment / review
Diuretic	no	yes: breathlessness, oedema, can reduce hospital admissions	dehydration (uraemia), hypotension, hypokalaemia, gout (<i>most effective agent in acute phase is low dose prednisolone; watch for fluid retention. Use allopurinol for long term prevention once symptoms controlled</i>)	Require regular monitoring and readjustment of dose. Likely to be needed until the last days of life.
Hydralazine	yes, with long acting nitrates	no	flushing, GI upset, hypotension, systemic lupus syndrome with long term use	Very limited role. Only used if ACE inhibitor and ARB intolerant.
Nitrates	yes, with hydralazine	yes: sublingual nitrates may lessen dyspnoea	headaches	Standard treatment for angina. Very limited role in advanced heart failure. Only used if ACE inhibitor and ARB intolerant.
Spiro- lactone	yes	no	hyperkalaemia, GI disturbance, breast tenderness, gynaecomastia with spironolactone	Stop during any intercurrent illness which causes hypovolaemia. Stop if potassium rises (>5.5mmol/L).
Statin	yes	no	nausea, hepatic dysfunction, myalgia	Stop if side effects, and do not replace with other drugs.

* see current version of BNF or Summary of Product Characteristics for full list.

Note: advice on these issues can be sought from the heart failure team

Appendix 3 Suggested approaches to some difficult end of life questions

It is not possible to reproduce unique one-to-one interactions, and conversations such as these appear unnatural in print in what is inevitably an abbreviated form. The precise form of words is less important than the use of words and phrases with which the individual healthcare professional feels comfortable.

Explanation of diagnosis and its implications

This should ideally take place at the time of diagnosis.

'The tests show that your heart isn't working as well as it should be (and/or 'It looks as if there is some damage to the muscle and pump in your heart which has caused some weakness ... this doesn't usually just go away') – and that's why you've been getting more short of breath' (or other presenting symptom) . . .

'The medical term for this is heart failure - it was probably caused by ...'

'We don't have a permanent cure for this ...'

'But nowadays there's a lot we can do to help ... and I think you will feel much better when the tablets start to work ... there are also plenty of things you can do yourself which will help ...'

Addressing the possibility of sudden death

This may be raised by the patient:

'Am I likely to suddenly die?' ('That's what happened to x') or 'Am I likely to have a (another) heart attack?'

Possible response:

'Is that a question you ask yourself a lot?' ...

'It is true that we have to see that as a possibility.' . . .

and then take the dialogue on from there.

If an opportunity like this to raise the issue doesn't come from the patient a member of staff should raise it at a review appointment - for example, while going over again what the patient has already been told.

'Well, like other patients with heart failure, there is a chance that you could have a life-threatening problem with your heart ... with heart failure you can have sudden problems with the rhythm and/or the pumping of the heart ... these would be very serious and can sometimes be fatal/lead to death ...' there are a number of things we can do to make it less likely to happen ...'

Acute decompensated heart failure and/or hospitalisation

Possible questions:

'Why did it happen' ... 'will it happen again?'

Possible response:

'This does tend to happen sometimes'... after explaining the cause.

'there's a lot we can do, by working together, which will make it less likely to happen again ... but there aren't any guarantees . . .'

After the patient notices either a deterioration following hospitalisation or a gradual slowing down

'I think we will have to accept that you may not get back to where you were before'

'There are some things, I'm afraid, that we can't just put right'

'Perhaps we could talk through some of the other things we can do to make life easier for you.'

The start of advanced heart failure

'I think we've both noticed that you've been slowing down ... and the latest change in treatment doesn't really seem to have helped.'

Possible question:

'Am I going to die?'

Possible responses:

'Well, as you know, there is permanent damage to the muscle pump of your heart and this (the deterioration, slowing down) probably means that as a result your heart is getting a bit weaker'

'It does mean that as time goes by you will slow down ... and so we should be prepared for that ...'

'But there are other ways we can help with your symptoms by using different medicines (eg opioids for breathlessness) ... and if you agree we can try that.'

'And there may be practical things which would make life a bit easier...'

'I wonder if there are any other problems on your mind you'd like to talk through ...'

The doctor/nurse who is talking with the patient should know the basic statistics about prognosis.

Planning future care

*'Do you ever think about how you would like to be cared for if you became more ill?' or
'... when you know that you are likely to die?'*

*'Would you like to talk about your future care?' or
'Would you like to be more specific about your future care?'*

'Would it help to talk about how you would want to be cared for at the end? If you do, we can either do that now or later ...'

Discussion about deactivation of implantable defibrillator

This should have been discussed with the patient at the time of implantation by the cardiac team:

'What did the doctor who fitted this tell you at the time? ...'

There's no harm in repeating the message or, if the patient wasn't told:

'We know that the time will come when it (the ICD) simply won't work properly with your sort of heart problem. At that stage, leaving it switched on is likely to cause more distress than do good.'

... 'You won't feel anything (when it's switched off) and you won't suddenly collapse or anything like that – in fact you won't feel any different'

Not for resuscitation

'As you probably know - you may well have seen it on television - when the heart suddenly stops working properly it can sometimes be restarted with electric shock treatment. It's very effective for some heart conditions but not for others. It's something we really ought to talk about at some stage ... would you like to talk about it now?'

'I have to say that I don't think that your heart would respond - I just don't think it would work. Sometimes the heart is just too weak ... can you understand that - I wonder how you feel about it?'

The terminally ill: the patient is likely to die in the very near future

Possible question:

'Am I going to die soon?'

Possible responses:

'Has that been going through your mind - have you been thinking about it ... would you like to talk it through?'

'Well, we both know that we haven't been making any headway with your treatment for some time. So, yes, I do think you are right.'

'I'm afraid there really is nothing else we can do to change that ...'

If asked to be precise:

'Well, it may be a few days or it may be a bit longer – I can't be sure'

'But there is a lot we can do to make sure that you are comfortable - and that your sleep isn't disturbed. I'd like to talk this through with you and your (family/carers) - we won't do anything you don't agree with and without discussing it with you first.'

'But to begin with I would suggest that we simply stop any of the medicines which aren't helping you and the same with some of the tests you've been having ...'

Supporting patients and carers

*'... yes, that must be hard for you. What is it that you find most difficult?' or
'Is there anything that we could do to help?'*

'Are you feeling a bit frightened about the future?'

'How do you see your husband's/wife's illness?'

'Who supports you as a carer?' or 'Is there anybody who can support you when you find it difficult to cope?'

Appendix 4 Additional reading and resources

Index

Advance Care Planning
Advance decisions
Breaking bad news
Cardiopulmonary resuscitation
Carer support organisations
End of life care
Ethical issues
General Medical Services contract
Implantable cardioverter defibrillators (ICDs)
Palliative care education
Patient experiences: *You're Better Off With Cancer*
Patient support organisations
Spiritual care
The Adults with Incapacity (Scotland) Act (2000)

Advance Care Planning

A Guide for Health and Social Care Staff, End of Life Care Programme (2007).
<http://www.endoflifecare.nhs.uk>

Advance decisions

Advance decisions can be filed with MedicAlert UK for access by clinicians. Bracelets for patient use are also available. <http://www.medicalert.org.uk/reactin.asp>

Breaking bad news

Breaking Bad News website: <http://www.breakingbadnews.co.uk/>
This website is pharmaceutically sponsored and is designed to provide guidelines and practical suggestions on how to communicate any medical information effectively and compassionately, and respond to a patient's and family's feelings and needs. The information is general but resources quoted are cancer-related.

Cardiopulmonary resuscitation

Additional reading:

Ethical Decision Making in Palliative Care: Cardiopulmonary resuscitation for people who are terminally ill. *J R Coll Physicians Edin* 2002;32:280.

Levack P. Live and let die? A structured approach to decision making about resuscitation. *B J Anaesthesia* 2002;89:683-686.

NHS Lothian Do Not Attempt Resuscitation (DNAR) Policy, Revised Version 0707. ©Spiller, Murray, Short & Halliday, Lothian Health Board 2007.

Carer support organisations

The Princess Royal Trust for Carers provides a range of support for carers on their website: <http://www.carers.org/> Local organisations may also be available.

End of life care

Information and resources on end of life care are available from the following websites:

<http://www.endoflifecare.nhs.uk> The Department of Health (England) End of Life Care Programme was

set up to improve care at the end of life for all wherever they live. This website aims to support the programme by sharing good practice, resources and information.

<http://www.goldstandardsframework.nhs.uk> The official website of the Gold Standards Framework.

<http://www.gsfs.scot.nhs.uk> The official website of the Gold Standards Framework Scotland project.

http://www.mcpcil.org.uk/liverpool_care_pathway The official website of the Liverpool Care Pathway for the Dying Patient.

Ethical issues

Advice specifically on ethical issues is available from:

British Medical Association Ethics Department: tel 020 7383 6286

British Medical Association website: <http://www.bma.org.uk/ap.nsf/Content/Hubethics>

General Medical Council website: <http://www.gmc-uk.org>

National Network of Clinical Ethics Committees: tel 01865 226849

See also:

Nursing and Midwifery Council Code of Professional Conduct: standards for conduct, performance and ethics. NMC 2004.

Medicines, Ethics and practice: A guide for pharmacists and pharmacy technicians. Royal Pharmaceutical Society of Great Britain. 31st edition July 2007.

General Medical Services contract

The new GP contract and what it means for patients:

<http://www.bma.org.uk/ap.nsf/Content/registerhssurgery>

Implantable cardioverter defibrillators (ICDs)

Issues related to deactivation of ICDs are dealt with in the following articles:

Berger J T. The ethics of deactivating implanted cardioverter defibrillators. *Ann Intern Med* 2005;142:631-634.

Lewis RW et al. Withdrawing implanted defibrillator shock therapy in terminally ill patients. *American Journal of Medicine* 2006;119:892-896.

Palliative care education

The Scottish Partnership for Palliative Care website <http://www.palliativecarescotland.org.uk> contains information on palliative care courses and conferences in Scotland as well as specialist palliative care contact details.

Glasgow Caledonian University School of Nursing, Midwifery and Community Health will introduce a new module in 2008 in Providing End of Life Care for Patients with Advanced Heart Failure. This may be taken as a stand-alone module or used towards the award of BSc/BSc (Hons) Professional Development.

Patient experiences: *You're Better Off With Cancer*

You're Better Off With Cancer was a television programme which was also presented at 'Supportive and Palliative Care for Heart Failure', an event hosted by the Coronary Heart Disease Collaborative in December 2004 in London. Available from:

Executive Producer Ann Moir,

Quality Time TV - Tel 0208 746 1855. (File size 67MB - requires minimum 512k broadband connection - Windows Media Player - .wmv file) http://www.heart.nhs.uk/endoflifecare/6_taking_the_cardiac_view/6.2_resources_nhs%20640%20x%20480%20v3%20wmv.wmv

Patient support organisations

Information and support re heart failure for patients and carers is available from the British Heart Foundation website: http://www.bhf.org.uk/about_us/bhf_around_britain/scotland.aspx and from the Chest, Heart & Stroke Scotland website: <http://www.chss.org.uk>

Spiritual care

Training and resource information is available from:

Healthcare Chaplaincy and Training NHS Education for Scotland 2007:
<http://www.nes.scot.nhs.uk/spiritualcare>

Marie Curie Cancer Care – Spiritual and Religious Care Competencies:
<http://www.mariecurie.org.uk/healthcare>

Multi-Faith resource for NHS Scotland staff (November 2006):
<http://www.nes.scot.nhs.uk/documents/publications/classk/271106multifaithpublic.pdf>

The Adults with Incapacity (Scotland) Act (2000)

The Adults with Incapacity (Scotland) Act provides ways to help safeguard the welfare and finances of people (aged 16 and over) who lack the capacity to take some or all decisions for themselves, because of a mental disorder or inability to communicate. It allows other people to make decisions on their behalf. It also enables each of us to make arrangements for another person or persons to make decisions and manage affairs on our behalf, in the event of losing capacity in the future.

Information about the Act is available on the Scottish Government website at:
<http://www.scotland.gov.uk/Topics/Justice/Civil/awi>

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Appendix 6: acknowledgements

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