

# Improving the care of patients with advanced heart failure

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**ABSTRACT** A strategy for managing heart failure based exclusively on conventional treatment results in the majority of patients having inadequate symptom control, a poor quality of life and uncoordinated care. The Scottish Partnership for Palliative Care report *Living and dying with advanced heart failure: a palliative care approach* advocates that these problems should be addressed by the integration of conventional and supportive care; at present this rarely happens. The report's main recommendations are summarised and their relevance to the natural history of heart failure discussed for the benefit of the general and care of the elderly physicians who are responsible for the in-hospital management of more than 80% of heart failure patients. The recommendations are equally relevant to primary care teams. The problems to be addressed when devising a strategy to implement the recommendations are outlined.

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There are 90,000–100,000 people in Scotland with heart failure,<sup>1</sup> comparable to the prevalence in England. This figure is predicted to rise dramatically in the coming decades.<sup>2</sup> Optimum evidence-based conventional treatment improves the prognosis, symptoms and quality of life (QOL) of patients with heart failure, but there is a growing realisation that this alone, even when implantable devices<sup>3</sup> are included in the list of treatments, does not address all of the patients' needs.

*Living and dying with advanced heart failure: a palliative care approach* is a policy document commissioned by the then Scottish Executive from the Scottish Partnership for Palliative Care (SPPC) in 2004. This was in response to the Coronary Heart Disease/Stroke Task Force report of two years earlier, which specifically noted the palliative care needs of heart failure patients. The SPPC report was presented to the Scottish Parliament cross-party group on palliative care in June 2008 and has now been published by the SPPC in collaboration with the British Heart Foundation (Scotland).<sup>4</sup>

During the decade prior to the report's publication it had been repeatedly documented that symptom control in heart failure patients was inadequate,<sup>5,6</sup> the QOL was uniquely poor; the care provided was uncoordinated,<sup>7</sup> and that to address these problems required a strategy in which conventional treatment is integrated with a programme of supportive (palliative) care. Currently, this combined management approach is provided for only a small minority of heart failure patients. The implementation of the report's recommendations offers the prospect of improved symptom control and a better QOL, particularly for those patients in the more advanced stages of the disease.

The SPPC's remit was to:

- Identify key issues to be considered in making palliative care available to people with cardiac failure.
- Produce guidelines for good practice and make recommendations on service provision.
- Circulate and encourage adoption of these via cardiac and palliative care-managed care networks (MCNs).

However, these MCNs represent only approximately 5% of the healthcare professionals with responsibilities for the care of heart failure patients. For 95% of the time heart failure patients are cared for by their local primary care team and, when hospitalised, their care in more than 80% of cases is not supervised by cardiologists but by general or care of the elderly physicians.<sup>8</sup>

The aims of this paper are two-fold: to summarise the main recommendations of the report as they relate to the natural history of heart failure for non-cardiac physicians and to discuss the factors that will need to be addressed when devising a strategy for their implementation. The report emphasises five basic principles:

- Optimal conventional treatment should precede palliative symptom control measures.
- The important components of palliative care strategies are generic, not cancer-specific, nor are the benefits confined to patients who are terminally ill.
- Most of the palliative care needs of heart failure patients have been defined as requiring general palliative care (Table 1), not specialist palliative care.<sup>9</sup>
- This level of care should, after appropriate training, be provided by the patient's usual primary and secondary care healthcare teams. The personal

involvement of a palliative care specialist should only occasionally be necessary.

- All patients with advanced heart failure should be viewed as potential candidates for palliative care support which, when appropriate, should be integrated into their management plans to complement, not replace, conventional treatment.

Recent findings by Audit Scotland demonstrate that only approximately 10% of patients who would potentially benefit from palliative care have their needs identified.<sup>10</sup> Comparable findings are reported from England and Wales. A misunderstanding of the role of palliative care, for whom it is appropriate and at what stage of their disease it should be introduced is partly responsible for these findings.

The report explains the objectives of palliative care by comparing them to those of conventional treatment:

- The primary objectives of conventional treatment are to relieve symptoms, often using disease-specific measures, and/or to prolong life. It is tacitly assumed that an improvement in the QOL will follow.
- The primary objective of a palliative care strategy is to improve the QOL of any patients with a chronic progressive disease while acknowledging that the disease is incurable. This involves a range of generic strategies of which symptom relief is only one.

These objectives are achieved by concentrating on those aspects of treatment and management which might otherwise be overlooked:

- Open communication with patients and carers.
- The control of all physical symptoms.
- The provision of a model of care which ensures that, wherever possible, problems are anticipated (advanced care planning) and that support is available 24 hours per day when needed.
- Terminal care.

Each of these areas of care is demonstrably lacking from the management of heart failure.<sup>11</sup>

## THE CLINICAL AND SOCIAL IMPACT OF ADVANCED HEART FAILURE

As stated in its title, the report primarily addresses the problems of patients with advanced heart failure. This term is often used loosely as being synonymous with 'severe' heart failure, but it has been objectively defined to include the following features:

- The presence of severe left ventricular dysfunction (e.g. ejection fraction <30%).
- Severe symptoms (breathlessness, fatigue and/or oedema) at rest or on minimal activity (New York Heart Association [NYHA] functional Class III or IV).
- Persistence of these symptoms despite attempts to optimise standard therapy.<sup>12</sup>

**TABLE 1** NICE definition of 'general palliative care'<sup>9</sup>

• Assessment of patient and carer need for support
• Open and sensitive communication
• Co-ordination of services throughout 24 hours and across administrative boundaries
• Basic level of symptom control
• Psychological, social, spiritual and practical support
• Appropriate referral for specialist palliative care

In addition, many such patients will have had episodes of pulmonary congestion or of peripheral oedema, been hospitalised within the past six months and been evaluated for cardiac resynchronisation therapy (biventricular pacing) – although in practice this latter 'criterion' is often not applied.

The onset of advanced heart failure is not a sudden event; it is part of the gradual deterioration that characterises heart failure and therefore only identified with hindsight. The possibility that this stage has been reached should always be considered if a patient's condition appears to be static or deteriorating despite the maximum tolerated guideline-based medication, since it identifies a pivotal stage in patient management:

- By definition, conventional treatment will not result in further symptomatic improvement. Consequently, the use of generic (palliative) symptom control measures should be considered.
- Hospitalisation is common, triggered by worsening heart failure, its complications, medication-related problems or a comorbidity.
- Patients are increasingly housebound and, especially those who are older and/or female, socially isolated.
- It is still commonly quoted that the annual mortality of advanced heart failure is approximately 50%, although some defy this expectation.

Although the report concentrates on the care of patients from this point onwards in the disease trajectory, it also emphasises that the different elements of the palliative care strategy should be introduced when the need arises (for example because of poorly controlled breathlessness) and not solely on the basis of the severity of heart failure. The major exception to this time frame is the importance placed on the way in which doctors and other healthcare professionals communicate with the patients throughout the course of the disease.

## SYMPTOM CONTROL

**RECOMMENDATION 1:** All patients with advanced heart failure should be provided with... optimum cardiological management. (This and all subsequent recommendations in the text are direct quotations from the SPPC report.<sup>4</sup>)

**RECOMMENDATION 2:** Health care teams should adopt a holistic approach... ensuring optimum... management of physical symptoms, including those relating to co-morbidities.<sup>4</sup>

A central tenet of palliative care is that all symptoms, not just those attributable to the primary diagnosis, should be optimally controlled. This objective is achieved for only a minority of heart failure patients.<sup>5,6</sup> Poor control of cardiac symptoms has been found in 40% of patients and of common non-cardiac symptoms (pain, anorexia/nausea, anxiety, depression and insomnia) in 50–60%. These latter symptoms are ubiquitous in chronic progressive diseases and the report recommends that they should be treated by members of the patient's normal healthcare team using local palliative care protocols.

Of the cardiac symptoms, the control of breathlessness is highlighted. In advanced heart failure it is, by definition, resistant to conventional treatment and is a major source of distress to the majority of patients and their carers.<sup>5</sup>

The recommendation is to prescribe an opioid, in combination with an anxiolytic if anxiety is a contributing factor, using a titrated dosage protocol.<sup>13</sup> Opioids are highly effective in treating the dyspnoea associated with acute heart failure, in chronic lung disease and in primary pulmonary and metastatic lung disease. However, trial evidence for their use in advanced heart failure is limited.<sup>14</sup> This, and unsubstantiated concerns about a risk of psychological dependence (addiction), the development of tolerance and the risk of physical dependence,<sup>14–16</sup> explain the continuing but unjustified reluctance to prescribe opioids in advanced heart failure.

## THE IMPORTANCE OF GOOD COMMUNICATION

**RECOMMENDATION 3:** Members of health care teams involved 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.<sup>4</sup>

Doctors have an overriding duty to discuss with patients the diagnosis, complications, prognosis and management of their disease.<sup>17</sup> But 'good communication' in the context of a palliative care strategy involves much more than this. It includes the initiation of discussion about a series of specific topics (see below) and a willingness to talk with patients about a range of personal concerns which are common to many people faced with a life-threatening diagnosis: these include social, financial, psychological and spiritual (in the widest sense of the word) issues.<sup>18</sup> Failure to address these concerns can lead to increased anxiety, depression and a worsening QOL.<sup>19</sup>

Until recently, this level of communication was widely regarded as the domain of palliative care workers, but the General Medical Council and the Royal Colleges now stress that it is important for all medical practitioners to acquire these skills.<sup>20</sup>

The specific issues, some generic and others predominantly relevant to patients with heart failure, which it is recommended should be routinely discussed with patients and/or their carers are:

- Breaking bad news (specifically about the implications of the diagnosis).
- Sudden cardiac death (SCD).
- Cardiopulmonary resuscitation (CPR) and Do Not Attempt Resuscitation (DNAR) orders.
- Deactivation of implantable cardioverter defibrillators (ICDs).

Healthcare professionals are often reluctant to address these sometimes difficult topics. The report describes and references how these difficulties can be overcome.<sup>18–22</sup> In terms of the appropriate time to raise these issues the following points are made:

- Discussion with the patient about the diagnosis, implications and management of heart failure should begin as soon as the diagnosis is confirmed.
- Approximately 50% of heart failure patients die suddenly, usually as a result of an acute coronary event or an arrhythmia. This occurs more often in the earlier rather than the later stages of the disease<sup>23</sup> and, consequently, this issue should be broached soon after diagnosis.
- Implicit in the high prevalence of SCD, and the variable rate of deterioration of those who avoid it, is prognostic uncertainty. This should be discussed openly; failure to do so is a common cause of patient anxiety.
- The discussion of CPR, DNAR and the deactivation of ICDs should not be left until the patient is terminally ill.

## A MODEL OF CARE

**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 when necessary.

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 con-

sultation should be in place for patients with complex needs.

4.5 Steps should be taken to improve the sharing of information within and between health care 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.<sup>4</sup>

There are a number of reasons why, having reached the stage of advanced heart failure, patients' needs for professional care increase:

- They have worsening physical limitations, notably intractable dyspnoea, fatigue and/or oedema.
- Complications of heart failure also become more common, e.g. the onset of atrial fibrillation and acute myocardial ischaemic events.
- The incidence of common co-morbidities (diabetes, anaemia, depression and renal dysfunction) increase as heart failure progresses.
- Medication regimens become more complex.
- The impact on patients' personal carers becomes more difficult and stressful.

These problems result in increasing demands on the primary care team and heart failure nurses, more frequent visits to hospital outpatient clinics and/or periods of hospitalisation.

The difficulties for primary care teams are compounded because patients may be cared for by different hospital medical teams during successive admissions. Inevitably, as more healthcare professionals become involved, a breakdown in the lines of communication occurs between professional groups and patients, and poorly co-ordinated care becomes more likely. The report makes two main recommendations to address these issues: firstly, that the Gold Standard Framework (GSF)<sup>24</sup> should be more widely implemented and, secondly, that there should be a greater role for heart failure specialist nurses (HFSNs).

### **The Gold Standard Framework**

The objective of the GSF is to improve the quality of all aspects of care of patients living in the community who have a chronic progressive disease and who, it is thought, might be in the last year of life. It is therefore relevant to all patients with advanced heart failure. It is recommended by the Department of Health's End of Life Care Programme in England<sup>25</sup> and an adapted version is widely used in Scotland.<sup>26</sup> It prioritises three principles:

- The identification of patients in need of supportive care.
- The assessment of their symptoms and treatment preferences and any other issues which concern them.
- Planning care which prioritises these needs and preferences, in particular allowing people to live and die where they choose.

It also encourages:

- Anticipatory care.
- The development of multidisciplinary working.
- Improved communication between individuals, teams, patients and carers.
- The introduction of a strategy to ensure integrated 24-hour care when needed.

As a patient's condition deteriorates, the provision of 24-hour care in the community becomes increasingly important if they are to remain in their own homes and out of hospital. Currently, however, there is no satisfactory strategy that will consistently deliver this level of care, a situation that has arisen since the introduction of the new General Medical Services contract. All out-of-hours (OOH) services are now organised by NHS 24 and, as a result, patients who require OOH medical advice are rarely seen by healthcare professionals who know and understand their treatment and circumstances. This is compounded by the current lack of appropriate computer software to facilitate rapid access to patient records for OOH staff. NHS boards are specifically required to address this latter problem in the Government's recently published national action plan *Living and dying well*.<sup>27</sup>

The GSF has been implemented in 70–80% of practices in England and Scotland but currently provides predominantly for the needs of cancer patients. A major barrier to its routine implementation in patients with advanced heart failure is that in most cases their clinical status is not well documented and therefore their need for supportive care is rarely assessed.

### **The role of the heart failure specialist nurse**

Heart failure specialist nurses have established themselves as being central to the management of heart failure patients; they effectively optimise and monitor patients' medication, their involvement significantly reduces the high incidence of rehospitalisation and they are adept at identifying patients who have reached the stage of advanced heart failure and are therefore able to address these patients' problems. With few exceptions, HFSNs accept referrals from within the hospital and from the community<sup>28</sup> and they also play an important role in the education of primary and secondary care staff. On this basis they are ideally placed to take on the key role of co-ordinating patient management across the primary/secondary care boundary thus facilitating the implementation of this important component of the GSF.

## **TERMINAL CARE**

**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 should be implemented such as the Gold Standards Framework

for coordinating care of patients with advanced heart failure, and the Liverpool Integrated Care Pathway for managing the last few days or hours of life.

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.<sup>4</sup>

The report recognises that, as in other progressive diseases, there are no specific signs or symptoms to indicate when a patient with heart failure is terminally ill, but that there are generic and heart failure-related pointers to this being a strong possibility (Table 2).

Doctors often fail to recognise, or to accept, when a patient is terminally ill. This may be because medical training, quite rightly, prioritises curative as opposed to palliative treatment. But in some cases there are sound clinical reasons for delays, for example to ensure that a reversible precipitant of the patient's deterioration has not been overlooked and that alternative combinations of medicines have been tried. However, persisting with an unrealistically optimistic management strategy frequently results in patients having inappropriate treatment during the last few days of life, such as artificial ventilation, cardiopulmonary resuscitation or parenteral nutrition.<sup>29</sup>

The report recommends that, when it seems likely that the patient will die within the next few days, and after discussion with the patient and/or carers, several steps should be taken, including:

- Discontinuation of 'active' treatment. This will usually include the standard drugs used to treat heart failure: angiotensin-converting enzyme inhibitors, angiotensin receptor blockers, beta blockers plus antiarrhythmic drugs and aspirin although a loop diuretic may give continuing symptomatic relief.
- Discontinuation of the usual clinical observations.
- Review of advance decisions and preferred place of care.
- DNAR and deactivation of an ICD should be discussed if not previously done.
- Implementation of an integrated care pathway (see below).

### The Liverpool Care Pathway

The Liverpool Care Pathway for the Care of the Dying Patient (LCP)<sup>30</sup> is recommended by the NHS Modernisation Agency and by the SPPC. It is a multi-professional generic document detailing all aspects of intervention and care for the dying patient, including the points listed above. It is appropriate for use in hospitals, hospices, care homes and community settings and is particularly valuable for non-palliative care specialists. Specific adaptations have been made for its use with

**TABLE 2** Common findings in heart failure patients likely to die in the near future<sup>4</sup>

<b>Generic indicators</b>
• Unable to take oral fluids/medication.
• Increasingly withdrawn or unresponsive.
• Increasingly weak/exhausted.
• Bed-bound.
<b>Pointers related to advanced heart failure</b>
• Previous hospitalisation within the past few months, or frequent outpatient visits, without significant improvement.
• No further interventions likely to improve the patient's condition.
• No reversible cause of current deterioration.
• Deteriorating renal function.
• Hypotension and persistent tachycardia at rest.
• Life-threatening co-morbidity (such as chronic obstructive pulmonary disease).

heart failure patients.<sup>31</sup> It is designed to ensure that all necessary regular observations are undertaken and that medication is prescribed to relieve physical and mental distress. It does not dictate specific medications: it is assumed that local palliative care guidelines will be used for symptom control.

### OUTSTANDING ISSUES

The report's recommendations highlight the importance of optimising both conventional treatment and palliative support. But the remit for the report's working group was only to make recommendations. It was not required to provide a strategy for their implementation. However, recommendations to improve performance in any sphere of activity are ineffective without a strategy for their implementation.

Implementation is relatively straightforward when, as is usually the case, the disease in question is easily identified, the intended intervention is in line with the prevailing philosophy of care and the necessary knowledge or skills can be readily acquired by the patient's healthcare team members.

However, the situation is quite different when the objective is to improve the care of patients with advanced heart failure. The significance of advanced heart failure often goes unrecognised and consequently patients' need for additional medical and nursing support at this stage of their disease is usually overlooked. In addition, members of medical teams who care for these patients need to acquire skills and expertise in a treatment strategy (palliative care) of which few have personal experience.

A strategy to fill this skills and knowledge gap will have to take account of a range of other issues in addition to those just noted. The necessary training will require a significant time commitment from trainers and trainees extending over a number of weeks, particularly to acquire the necessary (general) palliative care skills. Some healthcare professionals will be either unwilling or unable to make this commitment. In Scotland, only 6% of cardiologists are designated heart failure specialists. Not all of the other cardiologists are involved in the care of heart failure patients, but those who are provide advice for other physicians and for primary care on the management of heart failure. It is, however, unrealistic to expect that more than a minority of them would consider that training in palliative care should take precedence over their existing clinical commitments. The same is true of the general and care of the elderly physicians who are responsible for the care of 80% of hospitalised heart failure patients, and it is also likely to apply to many doctors in primary care. This is in keeping with a widespread perception within the profession that end-of-life care is predominantly a nursing role.<sup>32</sup>

Training in the management of heart failure (specifically the identification of advanced heart failure) and in general palliative care should therefore be focused on those healthcare professionals who have regular contact with the patients and who are enthusiastic about implementing the report's recommendations. Based on the mix of delegates who attend meetings on these

subjects this will be predominantly nurses: HFSNs, medical and geriatric ward nurses, palliative care nurses and practice nurses. Although many degree courses in nursing now include a palliative care module, the quality varies and all would require additional training (personal communication from a Macmillan nurse education facilitator). Finally, the logistics of providing support for patients will vary with location, and training programmes will have to be adaptable.

A similarly comprehensive programme should be integrated into undergraduate nursing (and medical) degree courses to reduce the need to provide ongoing educational programmes for established but untrained staff.

In its report *Living and dying well*,<sup>27</sup> the Scottish Government indicates that financial support will be provided to improve the end-of-life care for patients with an incurable progressive disease. Bearing in mind that HFSNs have been identified as central to the provision of what will effectively be a new service, some of this support will be required to increase their numbers which currently are inadequate even to fulfil their present responsibilities.<sup>8,33</sup>

The important recommendations of the SPPC report outlined above have the potential to make a significant improvement to the quality of the lives of patients with heart failure and that of their carers. But this will only be achieved if implemented using a funded, focused strategy.

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## ADDITIONAL RESOURCES

A comprehensive resource list is given in reference 4, from which the following have been selected.

- **Breaking bad news:** <http://www.breakingbadnews.co.uk>
- **Cardiopulmonary resuscitation:** *Additional reading:* National Council for Hospice and Specialist Palliative Care Services, the Association for Palliative Medicine. Ethical decision making in palliative care: cardiopulmonary resuscitation for people who are terminally ill. *J R Coll Physicians*

- **Implantable cardioverter defibrillators:** British Heart Foundation. Implantable cardioverter defibrillators in patients who are reaching the end of life. London: British Heart Foundation; 2007. Available from: <http://www.bsh.org.uk/portals/2/icd%20leaflet.pdf>
- **Palliative care education:** <http://www.palliativecarescotland.org.uk>
- **Patient support organisations:** [http://www.bhf.org.uk/about\\_us/bhf\\_around\\_britain/scotland.aspx](http://www.bhf.org.uk/about_us/bhf_around_britain/scotland.aspx)
- **Spiritual care:** <http://www.nes.scot.nhs.uk/spiritualcare>

## EVENING MEDICAL UPDATE PROGRAMME FOR 2009/2010

■ <b>Changes to PACES</b>	22 September
■ <b>Cough/Radiology</b>	20 October
■ <b>Fever</b>	17 November
■ <b>Limb pain/Swelling</b>	1 December
■ <b>Rash</b>	26 January
■ <b>Poisoning</b>	23 February
■ <b>Blackout/Collapse</b>	23 March
■ <b>Abdominal pain</b>	20 April
■ <b>Breathlessness</b>	25 May
■ <b>Chest pain</b>	15 June

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