# Extending palliative care to patients with heart failure

***The pathophysiology and targeted management of heart failure is now well understood. However, patients may live for some years with significant symptoms and resultant reduced quality of life. Good supportive care and access to specialist palliative care is important for optimum care for patients living and dying from heart failure.***

Tailored therapy, self-management programmes and keyworker support from nurse specialists have transformed the care of patients with heart failure. However, as a progressive disease, unless the patient dies from a sudden arrhythmia or co-morbidity, an end stage of advanced illness leading to death from heart failure is a reality. In the 5 years following diagnosis mortality is estimated at 45–75% – similar to many cancers (Cowie et al, 2000; Stewart et al, 2001). These figures have probably improved since then, but patients with heart failure still die from their disease and are symptomatic in the last stage of their illness. The *National Service Framework for Coronary Heart Disease* (Department of Health, 2000) highlighted the need for a palliative approach and access to specialist palliative physicians for patients with advanced heart failure, and the European Society for Cardiology has published a consensus statement on palliative care for patients with heart failure (Jaarsma et al, 2009).

## Problems in extending palliative care to patients with heart failure

In spite of this recognition, there is still a poor understanding by patients and their carers of the illness and its potential severity (Rogers et al, 2000, 2002; Murray et al, 2002). Likewise, clinicians can be slow to recognize that disease-directed treatment options are running out and that supportive and palliative care is becoming the main focus. The emphasis may be on disease-specific treatments to the exclusion of palliative care support, even in patients who are highly symptomatic and requiring psychological support, because 'there's still a lot we can do' and 'we're not at that stage yet', instead of extending the team to include relevant clinicians who will be able to help.

One of the main difficulties is that patients with heart failure can have a slow decline in function punctuated by acute episodes of cardiac decompensation with fluid overload (Murray et al, 2005). This initially responds to treatment returning the patient almost back to his/her pre-deteriorated state. Thus the patient, his/her family and clinicians become used to intermittent 'scares' followed by recovery. The fact that the patient continues to slowly deteriorate, with worsening breathlessness and fatigue, increasing number of hospital admissions, worsening renal dysfunction and persistent hypotension, and becomes unable to tolerate cardiac treatment may not be addressed. Consequently, the decompensation that then leads to the patient's death is not recognized. Death then occurs with and despite aggressive management in an acute setting even though there is evidence of poor prognosis, often going back several months, if an overall context is taken. This is reflected in an unrealistic faith in attempted cardiopulmonary resuscitation by patients, who may have had a successful resuscitation in the past when their myocardium was less damaged, and by clinicians, who fail to assess the underlying state of the heart and the likely futility of such an attempt in someone with severe end-stage disease.

The last few decades have seen experiential training in advanced communication skills for those working in oncology because of the documented patient and carer distress resulting from inadequate communication (Maguire and Faulkner, 1988; Maguire and Pitceathly, 2002). Communication skills training also helps prevent clinician burnout and maintain a sense of personal effectiveness (Ramirez et al, 1996). However, few clinicians in cardiology have had such training and understandably some feel unsure and uncomfortable discussing worsening disease, a change in aim of treatment, access to palliative care services and plans regarding death and dying. Clinicians may have little experience of exploring patient concerns and wishes, and of maintaining hope with realistic goals, while telling the truth.

Lastly, coordination of care and communication between settings is often poor, especially for those patients with 'revolving door' admissions, admitted under the care of a different consultant each time. Time spent cutting across, what is all too often, a primary–secondary care divide allows a consistent approach to care and may prevent inappropriate emergency admissions.

## Symptom control

Good symptom control begins with a full assessment of the problem, including psychosocial factors and impact. Optimization of cardiac treatment is paramount, and may not have been done or temporary reductions in treatment may not have been re-titrated when the issue was resolved. Many patients with heart failure have not been seen by a

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cardiologist or assessed for device therapy. Many elderly patients have co-morbidities and their care may be improved by an overall assessment by a care of the elderly physician.

## Breathlessness

Reversible factors such as decompensated failure, infection, pulmonary embolus and suboptimal management of chronic pulmonary disease should be looked for and treated. Other co-morbidities such as lung cancer may be found. Paroxysmal nocturnal dyspnoea as a result of decompensation may be mimicked by alarming nocturnal 'breathlessness' episodes caused by sleep apnoea. A careful history and examination is needed, and a sleep history from a partner if available. Despite optimal cardiac treatment and dry weight breathlessness may persist for reasons such as enhanced chemosensitivity resulting in abnormal ventilatory patterns (Clark and McDonagh, 1997).

Management includes breathing training and exercise programmes, with anxiety management (Beniamionovitz et al, 2002; Moore et al, 2002; Yu et al, 2007) and practical help like the provision of a hospital-type bed where not only the head, but also the feet, can be raised to prevent slipping down in the night if necessary. A hand-held fan may reduce the sensation of breathlessness and should be tried before oxygen in the absence of any other indication for oxygen (Schwartzstein et al, 1987; Booth et al, 2004). Patients with compensated heart failure are rarely hypoxic, and even in the presence of hypoxia, oxygen does not appear to help the sensation of breathlessness significantly, although the flow of cold air that it may provide may help. Oxygen may be needed for other reasons such as confusion which may result if the patient is hypoxic. If sleep apnoea is shown with episodes of nocturnal desaturation, nocturnal oxygen or continuous positive airways pressure may be helpful to prevent nocturnal distress and daytime somnolence. Low dose opioids (e.g. morphine 2.5–5 mg four times daily or a morphine-equivalent dose) (Johnson et al, 2002) may help, taking care with opioids that are renally excreted in the presence of renal dysfunction, and low dose benzodiazepine (e.g. lorazepam 0.5–1 mg sublingually) where panic is a prominent feature.

## Fatigue

Fatigue is common and debilitating. Reversible factors include over-diuresis with a postural drop in blood pressure, hypokalaemia from loop and thiazide diuretics, anaemia, insomnia or depression. Exercise training programmes have an important role and should be encouraged.

## Pain

Pain may be caused by ischaemia, gout or musculoskeletal co-morbidities. Optimization of cardiac medication is important, and consideration of other measures such as transcutaneous nerve stimulation (in the absence of devices) may help. The World Health Organization (1996) analgesic ladder is applicable. Non-steroidal anti-inflammatory drugs should be avoided in heart failure because of the risk of decompensation as a result of fluid retention (Heerdink et al, 1998). Colchicine or low dose steroids are preferable for the treatment of acute gout.

## Other physical symptoms

Loss of appetite can be a problem for many patients and takes away one of life's pleasures. Attention to calorie intake is important, but the weight loss of cardiac cachexia in end-stage disease is a worrying feature (Anker et al, 1997a,b). Poor appetite may just be the result of ill-fitting dentures, the patient being too tired to prepare food, or nausea. A dietary assessment is important with use of protein-calorie supplementation if necessary. If, however, it is judged that this is a result of end-stage disease cachexia, then encouraging the patient to eat little and often for enjoyment can sometimes release him/her from 'force feeding'.

Nausea may be caused by medication (spironolactone, digoxin), renal dysfunction, liver engorgement and gut oedema, or simply poor oral hygiene. An anti-emetic such as metoclopramide or domperidone 10–20 mg three or four times daily or a small dose of haloperidol (1.5 mg once a day) may be required. As cyclizine may impair cardiac function (Tan et al, 1988), it should be avoided if possible, but it should not be withheld in a symptomatic end-stage patient if it is the only anti-emetic available.

Constipation may cause much misery, particularly in patients with restricted fluid intake, weakening musculature, poor mobility, breathlessness and fatigue. Unless there is another indication such as irritable bowel disease, bulk laxatives such as ispaghula husk should be avoided as a good fluid intake is required for them to work best.

Dry skin can be an overlooked but significant problem. Good skin care with regular use of emollients is necessary to prevent breaks in the skin which allow a portal of entry for bacteria, leading to cellulitis.

## Psychological symptoms

There is an increased prevalence of depression compared with the general population. Heart failure patients who are depressed are more likely to be admitted to hospital and more likely to die (Murberg et al, 1999; Guck et al, 2003). Depression affects the patient's ability to make decisions and understand his/her medication regimen resulting in poor compliance. Depressed patients are also more likely to develop heart failure. Non-pharmacological management includes exercise and cognitive behavioural therapy programmes if available (Luskin et al, 2002; Koukouvou et al, 2004). Antidepressant medication such as selective serotonin-reuptake inhibitors and tetracyclic antidepressants appear to be safe although tricyclics are pro-arrhythmic and should be avoided (Alvarez and Pickworth, 2003).

Anxiety is also common, and may feed into an anxiety–breathlessness–anxiety cycle. Anxiety may respond to a full assessment, addressing specific symptoms and issues of concern. Non-pharmacological approaches to anxiety management should be used, and intermittent use of benzodiazepines for panic may be helpful, although

long-term benzodiazepines should be avoided if possible because of the risk of memory loss and falls. Anxiety states, rather than intermittent panic, may benefit from selective serotonin-reuptake inhibitors.

## Care of the dying

### Advance planning

Planning for the dying phase can be discussed considerably before it is apparent that the patient is imminently dying. Signs of progressive heart failure provide dynamic poor prognostic markers that can inform the question 'Would I be surprised if the patient died in the next year?' (Rector and Cohn, 1994; Rector et al, 2006) and provide a background context to deciding on appropriate management choices in the event of a deterioration in clinical condition. For example, a patient with New York Heart Association class IV (symptoms every day and at rest) heart failure, who has had at least one hospital admission during the previous 6 months, is unable to tolerate angiotensin-converting enzyme inhibitors and beta blockade as a result of persistent hypotension, has resistant oedema, has increasing diuretic requirements with regular need for parenteral administration, persistent low serum sodium and albumin levels, rising brain natriuretic peptide levels, worsening renal dysfunction (Smith et al, 2006) and persistent anorexia and weight loss (Anker et al, 1997b) is very unlikely to respond to inotropes in the event of a serious deterioration and even less likely to have a successful outcome from attempted cardiopulmonary resuscitation or discharge from an implanted cardioverter device.

Advance planning, which includes sensitive exploration of both patients' and carers' wishes about care, particularly with regard to place of death, can make the difference between a patient dying at home with those around him/her fully prepared or by default in hospital still in the throes of active and invasive treatment. It also prevents inappropriate use of emergency services and acute hospital beds.

Planning may include discussions about 'do not attempt resuscitation' orders (Berger, 2003, 2004). This can be difficult: the patient may change his/her mind about previously expressed wishes, and the patient and clinician may disagree over whether an attempt should be made (Krumholz et al, 1998). However, as heart failure progresses, attempted resuscitation becomes a futile exercise. Guidance (British Medical Association et al, 2007) clarifies that the clinician is not obliged to offer or discuss futile treatment options with the patient, although some patients would value explanation of the reasons for such a decision and the discussion can be part of letting the patient be aware of how unwell he/she is. Informing family and carers of such a decision, particularly in a hospital setting where there may be erroneous assumptions about this area, is good practice. Where this has been discussed with the patient and the patient has clearly stated a wish not to be resuscitated, this should be communicated between healthcare settings, and for the patient who is at home, plans made about out of hours medical care. For example, if the patient does not wish to be admitted to coronary care because he/she does not wish to be resuscitated in the event of a cardiac arrest, but may need analgesia for ischaemic pain, then local arrangements should be in place to avoid the standard protocol of 'chest pain = blue light ambulance' (a sensible protocol to avoid delays in pain to intervention time, but inappropriate for the patient at end stage).

Likewise, arrangements should be made to re-programme any implanted cardioverter device to pacemaker mode to prevent the risk of distressing, potentially repeated clear conscious shocks in the dying phase (Mueller et al, 2003; Berger, 2005; Berger et al, 2006). The latter needs sensitive discussion in enough time to arrange for the pacemaker technician (or sometimes the company representative) to re-programme the device. Facilities and systems vary for this in different localities and the clinical team should be familiar with local procedures. Even if the patient dies with asystole, the implanted cardioverter device will need to be re-programmed to pacing mode before the mortician can safely remove it.

### Care in the last few days

The care prompted by the Liverpool Care Pathway is transferable to patients dying with heart failure (Marie Curie Palliative Care Institute Liverpool, 2008). Patients with heart failure may have some specific issues. Pulmonary oedema may not occur in the patient who, by this stage, is usually drinking very little, but it will be a problem for some. Parenteral furosemide is indicated, either by intravenous infusion or boluses, or by continuous subcutaneous infusion using a syringe driver (Goenaga et al, 2004; Verma et al, 2004). If the latter is used, care should be taken to insert the needle in an area free from oedema. Transdermal or buccal nitrates may also be useful in alleviating distress from pulmonary oedema. Skin care can be a challenge in a patient with gross peripheral oedema, but is very important to prevent infection and skin breakdown. Breathlessness may require opioids such as diamorphine (5–10 mg/24 hours by subcutaneous infusion initially and titrated using as needed breakthrough doses of 2.5 mg according to symptom control) and benzodiazepines such as midazolam (10 mg/24 hours by subcutaneous infusion initially and titrated using as needed breakthrough doses of 2.5–5 mg according to symptom control). If symptoms remain difficult, then the specialist palliative care team should be asked for advice.

## Conclusions

To extend palliative care to patients with heart failure, all practitioners involved in their care need to develop skills that include full holistic assessment of symptoms, teamwork and an ability to communicate effectively with patient, carers and other health-care professionals. Specialist palliative care teams can help with education, support and management of complex and persistent problems. Recognition of patients who are in the end stage of their illness is important to allow appropriate discussion,

choice and planning for the patient and family. The difficulties in prognosis make this challenging, but not impossible, in a significant number of patients. The developing links between cardiology, palliative care and primary care should be encouraged, with mutual learning and understanding contributing to better patient care. **BJHM**

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## KEY POINTS

- People with end-stage heart failure are highly symptomatic but may have less access to supportive and palliative care services, understanding of their illness and opportunity to contribute to advanced care planning.
- Excellent communication skills are required by all clinicians involved in their care in order to redress the issue.
- End-stage disease can be a challenge to recognize, but it is possible in many patients.
- An extended team approach, using a problem-based rather than prognosis-focused approach, is required.