Heart failure and hospice care
How to make a difference

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British Heart Foundation
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Foreword from Hospice UK

The British Heart Foundation estimates that over half a million people in the UK are currently living with heart failure. Like many other chronic conditions, its progression can be unpredictable and varies hugely from person to person. Clinical care for those living with heart failure is often excellent and is focused on relieving complex symptoms. However, it is so easy to miss the person in the midst of a complex condition; a person who is often confused, scared, worried about the future and facing unpredictable decline. People who are living and dying with heart failure can really benefit from specific, personalised care that can help improve their quality of life right up until their final moments. Hospices are well-placed to provide this.

I have seen first-hand how a person with heart failure can become invisible as multiple specialists focus on specific symptoms. My Gran lived with end stage heart failure for nine months. She bitterly regretted agreeing to open heart surgery that gave her an extra six months of life but unexpectedly ended her independence and ability to enjoy life. She wanted to talk to someone about the fact she knew she was dying and was frightened about what might happen to her, but even four weeks before death she was denied palliative care by a consultant convinced her condition remained curable. She was referred to a nursing home for rehabilitation but remained in bed and in a wheelchair. Finally she died without being able to discuss the fact that she was dying. It could all have been so different. I am determined that the benefits of palliative care will be available to all in need.

This guide aims to raise awareness of the need for earlier referral and targeted hospice care for people with heart failure, and we are so pleased to be collaborating with the British Heart Foundation and the team at the new Wolfson Palliative Care Research Centre. The partnerships we develop with other organisations will be vital as we work to improve access to hospice care, and we hope that this report will encourage hospices to develop similar collaborations with commissioners, cardiologists and other colleagues in primary care.

As we look ahead to the next fifty years of hospice care, it is vital that the hospice movement continues to evolve. We view Hospice UK’s new five-year strategy as the beginning of the hospice movement’s next stage: extending the reach of hospice care to people with any life-shortening condition, in any setting. This guide makes it clear that reducing inequality of access to palliative care for people with heart failure must be a key priority for all hospices. By working together with our colleagues in specialised fields, we believe we can provide equal access to hospice care and meet the needs of those living and dying with heart failure.

Tracey Bleakley
Chief Executive
Hospice UK
Foreword from British Heart Foundation

This is an important and timely guide, and makes a major contribution to improving the way we care for people with end-stage heart failure.

Heart failure is a common, progressive and distressing condition which can be disabling and life-limiting. However, the natural history of heart failure is unpredictable and there is no moment in the natural history of the condition when the priority of care shifts from curative to palliative care.

This guide sets out the principles and practical advice so that all agencies provide an integrated approach to improve the way we care for people with end-stage heart failure. The authors represent specialist cardiology, palliative care, and the multi-disciplinary team, mirroring the nature of end of life care for heart failure patients. The key starting point is a comprehensive assessment of the patient and family's needs.

As the local hospice is at the heart of its community, it provides the ideal place to enshrine the values and ethos of an integrated approach to care, attending to the clinical, social and spiritual needs of the patient. This approach can then engage and influence other local health and social care agencies.

The provision of care for those nearing the end of life is arguably the most discerning test of a modern health and social care system. It is recognised that the UK is doing well by international standards, but there is more to be done. Hospice UK is to be commended in providing the leadership and passion to raise awareness of the vital role that the 220 hospices in the UK play in caring for anyone with a life-threatening illness, and normalising dying, death and grief.

Dr Mike Knapton
Associate Medical Director
British Heart Foundation
Executive summary

This guide is intended for people providing and commissioning hospice services. Its purpose is to raise awareness of the need for a hospice-enabled approach to heart failure, and to suggest ways to engage with this issue using examples from services which have found creative solutions to move forward and overcome the challenges.

People with heart failure, and those family members and friends who care for them, have a high burden of unmet palliative care needs but have poor access to hospice services.

Although there are examples of hospices providing care for people with heart failure, the vast majority of people cared for by hospices are still those with cancer. This is despite emerging evidence that people with heart failure benefit from specialist palliative care. By opening hospice services up to this group of people, we hope that the quality of life and death will be improved for them and a current serious inequity in care addressed.

We hope this guide will encourage hospices to review their provision of care for people with heart failure and to take new steps to work collaboratively with their colleagues in cardiology, care of older people, primary care and others. There are several practice examples and numerous perspectives from patients, carers and commissioners.

Key points for change

• Incremental steps are often needed, starting with a behavioural shift to allow the formation of new relationships between clinical services.

• Hospices should be involved in service design and delivery for patients with heart failure.

• Mutual training and education should enable:
  » heart failure, care of older people and primary care teams to provide a generalist palliative care assessment and management
  » hospice staff to be competent in basic cardiac care supported by their cardiac teams.

• Hospices should be accountable to commissioners, providing audit data regarding provision for people with heart failure, agreeing realistic service improvement targets.

• Understand the strengths of hospice care and where it can make a significant difference throughout the heart failure trajectory.
Section 1. Why change?

Through a carer’s lens: Caroline’s Story

When Les was diagnosed with heart failure he was just told, “… you won’t live to see 80.” It wasn’t until 10 years later when our son was three months old that his condition seemed to deteriorate and he became more breathless and symptomatic. In the September he had a cardiac arrest while in the car with myself and our son. His cardiac resynchronisation therapy defibrillator device (CRT-D) activated and gave him a shock and Les survived. We called his CRT-D his ‘guardian angel’ and just assumed that if his heart stopped again this would just start it again. However, Les was very distressed and asked for mental health support but it was six months later before he got any.

The following year he went for a heart transplant assessment. Although Les thought about the enormity of what was to come, I never thought he would die. On reflection it would have been helpful to talk about this more. After his assessment we were told he had a one in 10,000 chance of getting a heart and the only other option would be to have a left ventricular assist device (LVAD) fitted, which was only used as a bridge to transplantation at that time. We left that meeting and cried. Three or four weeks later while on holiday Les had a cardiac arrest but this time, his CRT-D wasn’t able to re-start his heart. He died.

I wasn’t prepared to come home without my husband; no-one had spoken to us about this. There was so much stuff I didn’t know about when he died, things like financial issues, bereavement care and emotional support for me and my son.

‘Palliative care’ makes you think someone is going to die immediately, but if this was normal care for long-term life-threatening conditions it would help so many people to be prepared. I know I certainly wasn’t.

Why does this still happen?

Fifty years on from the founding of St Christopher’s, the first modern hospice, the overwhelming majority of people accessing hospice service are still those living and dying with cancer.

In 2014, the World Health Assembly resolved that palliative care, provided as an integrated component of universal health coverage, is an ethical responsibility of health systems.¹

The UK is one of only 20 countries in the world (8.5 per cent) to have a palliative care service which is adequately integrated into the health service.² Palliative care is an examined part of the undergraduate curricula at medical schools and specialist services have permeated into most hospitals and communities supported by the bedrock of primary care.

The 2015 Economist Intelligence Unit reported that the UK had the highest Quality-of-Death Index, prompting press releases about the UK being the best place to die because of the quality of its hospice provision and palliative care.³ In the UK, people do not have to worry about paying for palliative care, and do not have to wait to be referred until a clinician has made a certain pronouncement of death within a short time-frame. However, despite these factors, gross inequalities exist in access to palliative care services across age and diagnosis boundaries in the UK with 85 per cent of hospice inpatients having a diagnosis of cancer.⁴
Over half a million people in the UK live with heart failure, and 30-40 per cent of those diagnosed with heart failure die within one year.

As the disease progresses, symptoms and other concerns become burdensome, equal to those with cancer, with resultant reduction in quality of life across all domains (physical, psychological, social, financial and spiritual). Thus it would seem obvious that people living with heart failure should have access to a management approach which aims to:

“improve 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.” (WHO definition of palliative care, 2002).

However, despite national policy directives and some good practice examples of integrated care, people with heart failure remain disadvantaged, and many hospices remain uncertain of, or even have antipathy to, a role in their care. A recent All Party Parliamentary Group on heart failure noted that there had been progress towards cardiology and palliative care working together, but that this was slow and not consistent across the country.

**Figure 1. Complex needs and poor co-ordination of care for people with heart failure**

Used with permission from Karen Hogg
What is heart failure?

Heart failure is a clinical syndrome characterised by typical symptoms (eg breathlessness and fatigue) that may be accompanied by physical signs (eg raised jugular venous pressure, pulmonary crackles and peripheral oedema such as ankle swelling) caused by a structural and/or functional cardiac abnormality, resulting in a reduced cardiac output and/or elevated intracardiac pressures at rest or during stress.⁸

Essentially the heart pump is no longer working efficiently. There is often no single cause, although the underlying cause for the pump failure influences the disease course.

For many people (particularly older people) heart failure is not always the primary or main problem. Despite an increasing range of sophisticated medical treatments, the symptom burden for people with heart failure remains high and often unaddressed. The quality of life for many is poor and places a strain on their family caregivers.

Figure 2. Heart failure has an uncertain disease trajectory. People have varying palliative care needs

Used with permission from Karen Hogg
The economic and personal cost of heart failure is significant, largely driven by hospital admissions which are frequent and prolonged.

There may be many years of cardiac ill-health with no definitive moment where ‘end stage heart failure’ is diagnosed. Thus from the beginning of the condition, communication may be unclear. Many people would prefer to be cared for at home, but admissions often occur because of a ‘revolving door’ pattern associated with an uncertain disease trajectory coupled with multi-morbid conditions in the absence of coordinated alternative, supported care options.

Heart failure has a serious impact on family and friends providing informal care: again over a prolonged period of time, with little support or training. Conversations about treatment options are complicated. Patients and carers can feel overwhelmed by a professional’s agenda driven by best practice guidelines.

Most people and families living with advanced heart failure do not get the opportunity for advance care planning which could help address their needs and support preferences for care. A fundamental barrier to access is a poor understanding of heart failure as a life-shortening illness.

Clinicians are reluctant to initiate conversations about limitations in treatment or future concerns, despite recognisable signs that the disease is getting worse (kidney failure; reduction in medication doses due to low blood pressure; repeated hospital admissions, difficulties in maintaining fluid balance), for fear of taking away hope when further deterioration is uncertain.

However, as a recent American Heart Association policy statement urges:

“This communication simply must take place. Instead of serving as a reason to avoid conversation, uncertainty should be a trigger for exploration.”

Unless clinicians develop skills to have these conversations, and have them in time to help, it will be difficult to reduce the fear often expressed by patients about palliative care.

“She[mother] couldn’t walk from my table to my downstairs bathroom without stopping and bending over and literally fighting for breath so I ended up sitting her down and I said to her, ‘look we’ve really got to do something about this, it can’t carry on. With your permission I would like us to approach the hospice for you to have palliative care’, because palliative care had been suggested to her some three years ago and she went absolutely bonkers about it.

… So it feels like you are kind of battling on both fronts really because mum’s not that engaged in her own health decisions you’re having to advocate for her on that front, but also on the other side it feels like the healthcare professionals have their own agenda so you’re having to really kind of navigate this difficult course between the two of them.” Jean
Supportive and palliative care needs

Compared with cancer patients, those with heart failure have less understanding of their illness, have less access to supportive and palliative care over the years they could have benefitted\textsuperscript{12,13} and when the time comes, many die, by default, in an acute hospital bed while still receiving intensive and invasive medical interventions, as no other options have been discussed or offered.

Heart failure affects every aspect of life: physical functioning and ability to manage every day activities, psychological wellbeing, finances, work and hobbies. The role in the family is often severely disrupted with issues that could be as diverse as concerns about a poor sex life, to the challenges of looking after the grandchildren. Despite these issues, patients have less access to supportive care services, including specialist palliative care\textsuperscript{14} and these concerns are rarely addressed in the clinic by doctors and nurses.

“Oh the bath situation, I can get in the bath with not too much difficulty, but getting out is an absolute, I fall out. I actually, I actually do fall out the bath. I put my hands out to hit the wall other side, and getting dry is an absolute... major effort. In fact I couldn’t do it if it weren’t for these towelling robes, and I have to use one of them otherwise I couldn’t.”

“Breathlessness is always a problem... Particularly ... getting out of bed and particularly when, if I bent down, say if I bent down for two or three minutes, then the dizziness with the breathlessness is quite ... alarming ... That’s breathlessness and pain ... Most physical exertion causes some pain.”\textsuperscript{15}

A diagnosis of heart failure may not be considered as devastating as a cancer diagnosis by the general public, patients, family members or even some healthcare professionals. People with heart failure may feel very ill but look reasonably well in contrast to patients living with cancer whose decline may be clearly visible. This can lead to feelings of frustration, demoralisation, confusion and devastation for heart failure patients.

“But I’ve always been used to doing the manly things, like carrying out the rubbish, the big black ... bin that’s in, in the rubbish, now I have to watch her take that out. I have to watch her cut the grass, I have to watch her doing the heavy lifting and, you know, that, that drives me potty ... and every now and again, if she’s not around, I lift something a bit too heavy that I know I shouldn’t lift. I suffer for it, you know.”\textsuperscript{9}

A GP research database study of deaths during 2009 showed that while half of those dying from cancer were on the GP palliative care register, only seven per cent of those dying from heart failure were.\textsuperscript{16} Of those that were, a third were entered within a week of death, which is not long enough to support a person to die at home if that is their wish. This represents a gross inequality. As Murray and colleagues\textsuperscript{14} stress:

“Access to services should be based on need not diagnosis.”
Palliative care makes a difference

Until recently, one of the barriers preventing palliative care for people with heart failure was the lack of clinical trial evidence to show benefit. However, there are now three clinical trials designed to compare usual care and multi-professional specialist palliative care which show benefit for participants receiving specialist palliative care without reducing survival.17-19 Benefits were seen for quality of life, advance care planning and symptom control, and fewer re-hospitalisations. A recent systematic review and meta-analysis of three trials concluded that palliative care interventions reduced hospital readmissions by 42 per cent.20

These studies are small, and also do not tell us which patients need palliative referral, and who can be successfully managed by the usual care team. However, integrated working will support the heart failure team and facilitate timely referral or discussion with the specialist palliative care team, including admission to hospice units for symptom control or end of life care, or more intensive collaborative care at home. It should also be noted that none of the studies were conducted in the UK.

Summary

- Heart failure is a common condition, especially in older people, with a high mortality rate.
- People with heart failure have a significant burden of unmet palliative care needs.
- The impact on carers can be great and prolonged.
- Hospital admission is common in advanced disease, some of which could be avoided by coordinated care and advance care planning.
- People with heart failure often have multi-morbidity which adds complexity to their care.
- Supportive and palliative care should be provided according to need rather than prognosis alongside heart failure management, throughout the course of the illness
- Palliative care makes a difference.

More than 500,000 people live with heart failure in the UK

AND

More than 60,000 people die each year from heart failure in the UK
Section 2. A new model of collaborative care for advanced heart failure

Through a commissioner’s lens: Bromley Clinical Commissioning Group (CCG)

Bromley CCG recognised the challenges faced by many GPs in identifying, assessing and managing the complex care needs of those with advancing heart failure. These difficulties were compounded by the separation between our local service providers who manage heart failure in different ways, particularly in relation to cardiology, acute-based specialist palliative care, hospice services and community-based end of life support services.

Such fragmented practice leads to late identification with limited opportunities for holistic assessment of needs and preferences, advance care planning or care coordination which, in turn, leads to potentially avoidable unplanned hospital admissions. Individuals have therefore not been supported to die in their preferred place of residence in our locality. Quality of life for patients is further reduced by attendance at a busy emergency department; not ideal or pleasant for patients or their families.

Local hospices and palliative care teams are crucial in developing and implementing an integrated model of care. They play a central role in combined multi-disciplinary teams, supporting and participating in joint working alongside cardiology teams. Shared learning results from examples of high quality palliative care and difficult cases. Sharing of evidence-based palliative care assessment tools can also help raise awareness among cardiology teams and to gain a consensus around a more holistic, multi-disciplinary approach to assessing heart failure patients. These integrated care models have significant potential to be applied to other long-term conditions such as chronic obstructive pulmonary disease.

Key factors for success include:

- inclusion of hospices and palliative care teams in planning service model
- joint development of proposals, evaluation criteria, job plans and job descriptions
- joint heart failure/palliative clinical nurse specialist posts
- end of life/palliative care training in key resources used by both specialities
- strong working relationships between the different disciplines namely cardiology, community and acute-based specialist palliative care
- joint clinical involvement across different disciplines
- joint ownership of key outputs
- primary care involvement from an early stage.
We should be doing better

There have been calls for access to palliative care for this patient group for nearly two decades. A Pubmed search for ‘heart failure’ and ‘palliative care’ shows an exponential rise since the turn of the century (see Figure 3). In the UK we do not have the complication and excuse of restriction of palliative care resulting from health insurance plans as happens in the USA, and the model of integrated care is established. Yet people with heart failure still miss out.

Figure 3. Publications published each year on palliative care and heart failure

Models of care – problems, not prognosis

Heart failure care has often focused on treatment of the cardiac process itself, rather than assessing and managing the person as a whole in the context of their family and community.

Hospices and cardiology services alike remain concerned about the effect of workload, about inadequate skills, and of opening a flood gate of ‘unfixable’ need.

The uncertain course of the illness, the lack of a clear point at which palliative care could start, lack of communication, confidence in clinicians and poor clinical pathways between cardiology and supportive care services lead to an impasse.

In the words of the recent American Heart and Stroke Association consensus, “conversations simply have to happen”. The situation is untenable and we must do better. Successful services have found that the focus on problems rather than prognosis has allowed the flexibility of access which patients need.

Successful models of care have used an integrated approach based on identification and triage of problems rather than trying to pinpoint prognosis.

Attempts to identify the person in need of a palliative care approach in terms of prognosis (in the last six to 12 months of life) have proved unhelpful.
A study comparing the Seattle HF index with the Gold Standards Framework (GSF) Prognostic Index showed neither was clinically useful to help identify people who could be in the last year of life. However, the GSF index did identify over 80 per cent of those who had palliative care problems and may therefore be useful to identify those who would benefit from a palliative care approach.

What a difference … Joe’s story

Joe was a retired 72 year old who lived at home with his wife Jean. Joe developed severe aortic incompetence and endocarditis following a complicated Aortic Valve Balloon Valvuloplasty intervention in response to severe aortic stenosis.

Over three months Joe spent 92 per cent of his time in hospital: six hospital admissions under five different cardiologists accumulating 86 hospital bed days. Joe and Jean experienced a loss of autonomy, increased symptom burden, poor quality of life and care provision and a very real likelihood of dying in hospital without fully realising that death was even a possibility.

Despite such a large number of admissions, at no point was there any decision making regarding appropriate goals of care and maximum treatments. He had no advanced care planning discussions in anticipation of inevitable deterioration and associated preferred care wishes. There was no partnership working with wider professionals to comprehensively assess and manage unmet needs and coordinated facilitation of preferred care wishes effectively.

Over the next six months and following referral to the heart failure palliative care service, Joe and Jean learned to accept the reality and seriousness of the situation. With this came an acceptance of a new normality and empowerment to inform and plan shared decision making despite an uncertain trajectory regarding realistic goals of care, preferred care wishes and place of death. This was then communicated formally within the medical advance care plan which was shared with the patient and all professionals involved with the care provision, with key information being uploaded to the electronic out-of-hours system.

Joe and Jean experienced coordinated and responsive care at home despite several medical events which could have resulted in further hospitalisation; however, these events were managed effectively within the community care network. In doing so, Joe’s preferred place of care and place of death was facilitated effectively as he died peacefully at home with Jean by his side.

The practice examples in Section 3 of work being undertaken already by hospices confirm how teams can utilise their skills to respond to the needs of this neglected group.

Myth-busting

Integrated care assures the patient that they can concurrently receive appropriate heart failure care, and excellent supportive and palliative care. As palliative care according to need rather than prognosis becomes part of the ‘normal’ package of care, patients and families will pick up that it is a positive addition, enhancing the situation and not something to be afraid of.

“When you are first referred to palliative care and it is explained what that means, the first feeling is one of enormous relief.” (Widow of patient)
The terms ‘palliative care’, ‘hospice’, ‘end of life’ are often barriers to referral or discussion.

‘Palliative care’ is often misunderstood by clinician, patient and family alike as only being about care in the last days, and only for people with cancer – if this continues, palliative care will remain out of sight for people with heart failure.

‘End of life’ is the term embedded in UK policy as the ‘last year of life’, a term rooted in time. However, ‘end of life’ is almost uniformly interpreted by clinician and patient alike as the last few days. So any pathway or policy using the terms ‘end of life’ may be a barrier to many.

The word ‘hospice’ means death to many. Promoting the fact that hospices see patients in outpatient clinics, focus on living life to the full, and can work with the cardiac team requires a huge marketing exercise.

The inability to predict the clinical course of events deters clinicians from discussing aspects of advance care planning or integrating a collaborative cardiac-palliative care approach. Clinician discomfort is often further exacerbated by the belief that palliative care must wait until there is nothing else that can be provided from a cardiac perspective to modify the disease process.

These misperceptions lead to late identification of patients who would benefit from a collaborative cardiac-palliative care approach with the two approaches running alongside, neither detracting from the other.

Through a patient’s lens: Ray’s story

Well my wife died in the hospice so I’m aware of the general philosophy behind the name, which of course has a very comforting sort of feeling about it, although I was a little bit surprised that the areas they cover have increased so much because it was just the inpatient hospice in those days. But as I say, I was a little bit surprised but it’s probably going to work out quite well and it has done so far. I was a bit surprised to find how much they’re doing.

I think the main problems are the ones involving my leg and back to be able to get myself more mobile, if I wasn’t frightened of falling over because I can’t get up again, which is something I mentioned to the hospice physiotherapist.

Learning from each other

Most supportive and palliative care issues can be addressed by the usual team caring for the person, whether cardiology, primary care or older people’s care. However, the usual care team may not always be confident in the conversations or symptom control required – the collaborative approach allows sharing of care, with the heart failure team leading but supported by palliative colleagues.

One of the most important benefits of collaborative working is the mutual trust, education, support and learning that develops.

Heart failure nurses become more confident in symptom control issues and in initiating advance care planning conversations including goals of care, resuscitation decisions, preferred place of care and death. In turn, they are able to offer support and advice to the palliative care teams on the use of diuretic therapy to manage fluid balance for example, subcutaneous furosemide to manage fluid overload at the end of life, and will also support conversations about switching off implantable cardioverter defibrillators.
The teams support each other in decision making particularly around discontinuing medications in a safe way towards the end of life, ensuring that the patient and carers understand what changes are being made to medications and why.

Managing end of life discussions in the face of prognostic uncertainty is challenging for both teams and learning how to have these conversations in a way that maintains hope but on a background of realism is an essential skill to learn and will often be learned together. The cardiac teams frequently have longstanding relationships with their patients and will often be the most trusted clinicians to have these conversations.

Collaboration across different care settings

Collaborative work with palliative care involves engagement with hospital cardiologists who are then more likely to consider the net benefit of further invasive medical management, whether a referral to palliative care is needed, or a change in direction of care is appropriate.

There is also an impact on GPs who have sometimes been uncomfortable in managing patients with subcutaneous diuretics at home due to concerns about monitoring and management of electrolyte disturbances. The reassurance that the management plan has been devised by professionals from heart failure and palliative care working together is very powerful. Palliative care has an important role too, in recognising the importance of managing multi-morbidity in this patient group.

If palliative care and heart failure professionals working in the community, hospices and the acute trust collaborate, it is more likely that all agencies will be aware of the management plan; the right care, for the right person, in the right place at the right time.

Through a carer's lens: Mr Smith's story

After an acute episode requiring hospitalisation Mr Smith's son describes a balance of optimism and realism. His caring role is intense, but he is trying to identify where his limits lie and a routine that works. His choice to provide care for his father has impacted on his work. However, he has no hesitation about the choice he has made.

“No the breathing isn’t as good, the walking isn’t as good, the sight isn’t as good and possibly the confidence isn’t there either. I thought, I thought he was recovering at one time and recovery would be a matter of time; it might be six months, it might be a year but he’s not going to recover.”

“I’m sorting food out, I’m sorting medication out, I couldn’t do the cleanliness, the wash downs that the hospice carers do, I think time wise and ability wise I’m not up for that but he has the ileostomy, and I empty that bag in the morning in preparation just while we’re waiting for the carers to come.

I am working full-time. In my business I was working a 47.5 hour week and that’s what would be expected of me; I’m only working a 35 hour week and that’s having an effect, I’m not getting my job done as much as I should. I’ve not had a holiday for 10 years, you know, I can take a holiday and I can potter around here and get full enjoyment. I’ve not been in an aeroplane for 10 years, I will be doing so when he’s no longer with us but as I say, it’s a joy.”
Training initiatives

Palliative care needs to be embedded in higher specialist training for general internal medicine and cardiology. Elements of palliative care training are now part of the English cardiology higher specialist training for cardiology trainees, but a recent English survey showed they remained poorly equipped to address palliative issues, and were unsupported by their senior clinicians in this area of care, aggravated by poor engagement of the palliative care services with their teams.\textsuperscript{23,24} Initiatives such as fellowship opportunities to allow cardiology trainees to spend some time in specialist palliative care units or hospices and vice versa are welcomed but still unusual.

Targeted advanced communication skills training should be seen as important for both trainees and consultants.

Cross-city initiatives

Arising from the Caring Together programme in Glasgow, the Scottish Government in conjunction with the British Heart Foundation has funded a blended learning palliative-cardiology course of lectures and clinical shadowing. Multi-professional teams from each health board attend training as the ‘change agents’ for their region, thus rolling out integrated working for people with advanced heart failure at a national level.

Core components of integration

Local relationships and service context are fundamental. High quality palliative care for patients with advanced heart failure centres around the ability to deliver core components of care that can be adapted to local situations rather than the delivery of a set model that will work in all areas.

“Go around and see what is being done and then see how your own circumstances can produce another version; there is need for diversity in this field.” (Dame Cicely Saunders)

Figure 4. Core components of care

- Understanding what palliative care means and early identification
- Cardiology, holistic assessment and management
- Coordination, communication and MDT working
- Education and peer support

Patient centred care

Used with permission from Karen Hogg
What needs to happen?

1. Understanding that palliative care is the provision of an extra layer of physical and psychosocial support given to the patient and family alongside cardiology treatments intended to prolong life. The focus of care is on quality of life, maintaining appropriate treatments and therefore not only about death. This understanding helps with early identification of patients with palliative care needs rather than an approach to identify and manage only those thought to be dying.

2. Comprehensive cardiology and palliative holistic assessment of patient and family. This includes finding out what is most important to the person with heart failure rather than the professionals’ agenda (see Ray’s story).

3. Heart failure management plans and medical advance care plans. All patients should have patient specific tailored plans to fit the medical, device and palliative needs of the patient and family. In addition to usual advance care planning, a medical advance care plan manages the current issues and plans for the most likely events including guidance on the ceiling of medical care, a device deactivation plan and the patient’s goals and preferences of care. This can be challenging for people with heart failure, since due to its co-morbid nature a variety of specialties may be involved. Palliative care services can add a valuable case management component of negotiating plans across specialties.

4. Multi-disciplinary care teams, communication and networks of care. This approach to care can only be achieved by a multi-disciplinary team which spans primary and secondary care. Communication is essential to ensure that care plans are shared with all team members including out-of-hours services. Clear lines of communication allow the bidirectional flow of information for help, advice and support across primary, secondary care and inter-specialty which is often lacking. The wrong decisions are often made if this communication fails – electronic sharing of urgent care plans is paramount.

5. Assessment and support of family caregivers that extends into the bereavement period.

6. Education, support and development for team members so people with advanced heart failure have their general palliative care needs met and have timely referral to specialist palliative care for complex or persistent problems.

7. Research. People with advanced heart failure need access to evidence-based interventions and approaches, including palliative care. Both patients and their families/friends need access to information to support their choices about care options as the illness progresses.

8. A real and current understanding by cardiology teams of what local palliative services have to offer. For example, many hospices now have services and workshops to help people live with breathlessness and fatigue. Many have carers support services. Cardiology teams need to have the information, language and confidence to refer.

63% of people with heart failure have depression

Used with permission from Karen Hogg
What do hospice and palliative care teams need to know?

1. Heart failure referrals will not open the floodgates.
2. An integrated team will improve the care provided for the people with heart failure as a co-morbid condition, eg a person with lung cancer may have more problems from their co-morbid heart failure than their lung cancer.
3. An understanding of cardiac medications (what, why, and when to stop and when not to stop), when a cardiology review is needed, cardiac devices (what, when and what for).
4. The roles of the cardiology team, the care of older people teams and the primary care team, all of whom may be involved and have expertise to offer.
5. Palliative care team bring ‘value added’ communication skills.
6. A paced approach anticipating gradual change with periods of intense need interspersed with plateaus of stability.

What do heart failure clinicians need to know?

1. Confidence with conversations about the future, about goals and ceilings of care, for example, around device management.
2. Willingness to perform a holistic assessment and triage the concerns discovered, including those of the person’s family and friends.
3. How and when to work with the extended team, including palliative care and primary care.
4. Symptom control measures for pain, breathlessness, fatigue, oedema and anorexia.
5. The value of interventions to support ‘living well’ with heart failure, eg the rehabilitative palliative care components
6. Clear and realistic communication throughout the disease trajectory with patients and their families, and with other care providers.

Through a patient’s lens: Ray’s story

Well my most recent outpatient appointment was remarkably poor. It was supposed to be a heart failure one. I was supposed to see a consultant, I saw very jolly fellow, a little bit over jolly and they first did an electrocardiogram and the cardiologist who did that commented that I’ve got some arrhythmia and they of course took my blood pressure. But when the cardiologist discovered that I was more limited by my back and leg problems he gave up on the heart failure and decided to go on the standard one they have; trying to get me on to warfarin, which I don’t want to do because I had an episode of bleeding from the anus due to diverticular disease. They couldn’t promise me it won’t happen again. You know, I couldn’t really understand this doctor’s attitude he said, “but you know if you’ve got a bleed with warfarin any junior doctor can stop it”, but the junior doctor isn’t in my bathroom while I’m bleeding, he’s miles away [laughs] and I can’t get in without spraying blood all over the house, so he just made a recommendation and I think it’ll be left like that until next time but the length of time ‘til the next appointment of being a year is really rather silly, poor old NHS it must be overstretched.
Summary

- A prognosis-based approach misses the opportunity for people to access support and interventions for problems over a prolonged period of time, not just the final days of life.

- A problem-based approach whereby the cardiology, primary care and palliative care teams work together to address physical, social and psychological problems seems to be the most effective, although this is often reliant on interested individuals. We need to move past this to a position where it is standard care.

- Communication between and within teams, and between clinician and patients and family is integral.

- Clear pathways of referral and mutual education are needed.

- Education should be conducted systematically and include senior clinicians in both cardiology and palliative care.

Yet people cared for by hospice and palliative care teams =

- 70% cancer patients
- 4% heart failure patients

27% of deaths are from cancer
26% of deaths are from heart disease (including heart failure)
Section 3. Why hospice-enabled care for heart failure?

Through a carer’s lens: Jean’s story

I feel everyone is entitled to a good death, to have dignity, and from what I’ve seen, there wasn’t dignity in a lot of it and I don’t want that for mum or anyone; it’s the last great transition from this world to wherever. Surely you should have peace, care, consideration and mindfulness – my hope is that she will receive that at the hospice. The one person I know who passed away at home – it was not dignified and it was not peaceful. The one person who I know who passed away in a hospice possibly had the most dignified end and that is what I want for mum …

Hospices have much to offer. Some hospice and cardiology teams around the UK are starting to get to know each other. A survey of English heart failure nurse specialists showed that more had contact with their local palliative care teams in 2010 compared with 2005, palliative care education was widely happening, and agreed referral pathways were associated with increased use of palliative care services.27

Hospice care is needs led

Hospice care aims to respond to the needs of local people and groups. Hospice staff work hard to identify patients’ specific needs and preferences and those of family members and carers. The focus of hospice care is on quality of life regardless of prognosis, and response to the individual patient’s current needs is imperative, even if there is remaining uncertainty about how long someone has to live.

This is vital for people with heart failure. It is therefore appropriate that hospices should reach out to people affected by this diagnosis.

Heart failure patients spend 1 million days in hospital per year28

70% of heart failure costs are due to hospitalisation29
Hospice care is expert, flexible and timely

The expert nature of hospice care is derived from its exclusive focus on helping people with advanced and progressive disease and those close to them. The care is supported by multi-professional team work, a corporate commitment to the principles of palliative care and ongoing skills development on the part of staff and volunteers.

The flexibility and timeliness of hospice interventions, as the context changes, is one of the characteristics of hospice care. This is synergistic with care provided by specialist heart failure teams and others involved in the diagnosis and support of people with heart failure across primary and secondary health and social services. In order to ‘respond to patients’ specific needs and preferences’ the team must develop an understanding of the illness trajectory, the common problems encountered by patients and the treatment support options that help.

Practice example: St Christopher’s Hospice heart failure service evolution

We extended our service to people with advanced heart failure for three reasons:

1. Heart Failure accounts for about 20 per cent of deaths in our local population annually.
2. Service users with other diagnoses often have co-morbid heart failure.
3. In older people, our services extend beyond specialist palliative care to care coordination in individuals thought to be in the last year of life.

In 2011, a heart failure palliative care nurse consultant was appointed to develop a patient-centred model of care within the existing palliative care services with the following components: explicit management of the heart failure; supportive palliative care; case management; and evaluation.

Evaluation so far shows that patients and carers value a personal, flexible and skilled healthcare professional available ‘as needed’ rather than within a set review schedule. Our emerging evidence has allowed us to find common ground with cardiology and to collaborate with commissioners to implement a formal pilot integrating hospital, primary care and specialist palliative care. The testing, refinement, empirical evaluation and rollout will run through 2017 and 2018.

As part of the integrated service, a particularly valued aspect has been the rehabilitative palliative care service. This supports patients to identify realistic aspirations and develop a plan of how to achieve their goals. Patients can try the exercise equipment and receive a tailored programme that includes individual goals to measure functional change (“To be able to bounce on a trampoline with my grandchildren.” [patient 1]).

Through the programme we are also able to offer referrals to other services such as complementary therapy, occupational therapy, breathlessness management groups and social work. For many patients, the individualised nature of the programme is a relief and the fact that they can set their own pace helps them to trust that it won’t be too hard, too painful or too exhausting.
Hospice care is pioneering and innovative

A hallmark of hospice care is the aim to improve the lot of people who are dying or bereaved. Hospice boards should therefore consider investment in developments designed to improve care for local people with heart failure, their families and carers. Many aspects of hospice care require minor adjustment only and little additional resource to become suitable for this neglected group, integrated from early in the disease alongside active treatments. Hospices already have highly relevant skills in rehabilitation, providing practical support for living with fatigue and breathlessness, and help people to live with uncertain and variable health. Hospices are increasingly understanding their local reach and adapting to unmet need for groups of the population they do not yet serve, such as dementia.

Practice example: Saint Catherine’s, Scarborough

The integrated heart failure-palliative care service started in 2000. People with advanced heart failure have access to any part of the palliative care services according to need rather than estimated prognosis: outpatient, hospital inpatient or home visit medical review, day hospice, hospice at home, hospice inpatient care for symptom control (including parenteral diuretics which the service pioneered) or terminal care. Patients in the community also have access to a 24 hour helpline for advice, based at the hospice, irrespective of whether they need to access any other hospice service.

A palliative care nurse with a special interest in heart failure provides the liaison point in the hospice and the community heart failure nurses play a key role in coordinating and managing the patient’s care and support for the family. The standard information sheet about heart failure care is given to all new patients and includes information about the joint working with the hospice and emphasises the problem-based approach.

The service centres around a hospital-based palliative care-heart failure multi-disciplinary team (MDT) meeting attended by consultant cardiologists, consultant palliative physician, heart failure nurse specialist and hospital palliative care nurse specialists as needed. The MDT acts as:

- mutual education and support
- a referral pathway
- identification of service needs.

Excellent communication with primary care and out-of-hours service is emphasised. The service is underpinned by ongoing evaluation and research and a reduction in deaths in an acute hospital bed due to progressive heart failure has been demonstrated\(^{30,31}\).
Hospice care is integrated and education can be a “two way street”

In keeping with Dame Cicely Saunders’ original vision, hospices are key providers of education and training, providing learning opportunities for colleagues in primary and secondary care in the NHS and social care services including care homes. Although often established outside the NHS, hospices are now widely integrated into existing systems of health and social care. Improvement in palliative care access happens best when hospices work in partnership to address the multiple and changing needs of patients and their families and carers throughout the illness trajectory.

Integration works best if all involved recognise their strengths as well as gaps in knowledge and work together to design and deliver care.

Hospices can offer much in terms of planning and delivering holistic care focused on enabling people with heart failure to live and die well and providing support to families and carers pre and post bereavement.

In turn, hospice staff have much to learn from heart failure professionals. With increasing co-morbidity in older patients, heart failure is likely to be a condition contributing to symptoms even in cancer patients. So the skills to identify cardiac symptoms and understand medication is now crucial in all hospices, including those without dedicated heart failure services. Without integrated care and mutual learning, hospices risk providing a service ‘restricted’ to cancer patients, while providing suboptimal care to the people with heart failure as a co-morbid condition.

Practice example: Caring Together Programme, Glasgow

Starting in August 2010, the tripartite partnership between Marie Curie, the British Heart Foundation and NHS Greater Glasgow and Clyde was established to develop cardiology-led models of care (the Caring Together Programme) to improve the quality of, and access to, palliative care for any patients in the advanced stages of heart failure. The Caring Together heart failure and palliative care service is provided by a consultant cardiologist with an interest in palliative care and a heart failure palliative care nurse consultant.

The core components of care include early identification based on needs rather than a specific diagnosis or prognosis, a comprehensive cardiac and generalist palliative assessment to identify and manage needs, and advance care planning culminating in a patient specific Medical Anticipatory Care Plan (MACP) (Appendix 1). The MACP includes anticipated medical interventions to manage the patient’s cardiac condition(s), other medical conditions and how to manage their symptoms. This MACP is shared electronically with all members of the healthcare team including out-of-hours teams and involving specialist palliative care when needed. The MACP also documents important decision outcomes related to advance care planning including preferences of place of care/death, resuscitation status, defibrillator status and deactivation plans for cardiac devices.

A further core component is the development of cohesive multi-professional relationships across all care settings through a weekly palliative-cardiology multi-disciplinary team meeting attended by the cardiology medical team, heart failure nurse consultant, the heart failure liaison nurses, senior cardiology ward nurses, specialist palliative care, care of older people team, occupational health, physiotherapy, pharmacy, chaplaincy team and hospital discharge planners. The programme is underpinned by a service evaluation and research.
Hospice care engages with the community

The relationship between hospices and their communities is well established. Local communities continue to play a crucial role in the provision of hospice care via fundraising, volunteering and other forms of community participation. Hospices are well placed to galvanise community efforts to support people with heart failure and their families and informal carers. They are in a strong position to train volunteers to reach out to these individuals and to establish new models of care. Given the substantial burden of care on informal carers and the multiple challenges of living with a diagnosis of heart failure, input by volunteers could be very valuable.

Practice example: Hospice of St Francis, Berkhamsted and West Herts Community Heart Failure Team working together

The West Hertfordshire community heart failure nursing service was established in 2004 with support from the palliative care consultant at the Hospice of St Francis from its inception. Initially support was given through monthly action learning sets which involved cascading skills, discussing complex cases and offering emotional support. A grant from St James Place Foundation, awarded by Hospice UK in 2007, funded the Hearts and Minds Project, allowing the hospice consultant to further develop a comprehensive palliative care service for people with advanced heart failure in all settings.

Now in 2017, the consultant palliative physician attends the weekly acute NHS Trust cardiology meetings. Monthly community heart failure palliative care multi-disciplinary team meetings are held attended by community heart failure nurses, consultant cardiologist from the acute trust, palliative care consultant, community matrons and a GP. This fosters mutual training, education, support and discussion of ceilings of treatment.

Patient passports are being developed to ensure patients with end-stage heart failure have the correct information with them if admitted to hospital. The nurses are also in the process of redeveloping the palliative care pathways for heart failure patients including the development of a sub-cutaneous diuretics service for the dying patient at home or in a care home.

In addition to the exchange in knowledge and skills, the following changes have been seen:

- Consultant cardiologists are more likely to consider a more palliative approach.
- More heart failure patients are being referred to palliative care, have Advance Care Plans and Do Not Attempt Cardio-Pulmonary Resuscitation orders, achieve their preferred place of care and understand their choices.
- Fewer inappropriate transfers to the intensive therapy unit for haemofiltration/dialysis.
Hospices help people face the realities of living well with advancing illness and loss

Hospice care aims to help people cope with the multiple challenges associated with advancing illness through the delivery of individualised, compassionate care. People with heart failure, and those close to them, face similar experiences as those faced by people with other serious conditions.

Hospice staff are skilled in recognising when people are dying, are confident to have difficult conversations with patients and families about goals of care and provide relief from distressing symptoms. This approach would be highly complementary to the care provided by heart failure specialists.

Hospices work well with informal carers, assessing and supporting them pre and post bereavement and acknowledging their expert carer role. Informal carers of people with heart failure have significant needs and could benefit from the help available from hospices.9

Advance care planning for people who are coming to the end of their life is a growing area of need. An advance care plan, established early in someone’s illness, could be crucial in guiding decisions about their place of care, levels of intervention as their illness progresses and what matters to the patient and those close to them.

Practice example: Brent and Harrow Advanced Heart Failure Improvement Programme led by St Luke’s Hospice, Harrow

St Luke’s Hospice, Harrow led the formation of a partnership with the local NHS trusts to improve the management of patients with advanced heart failure. A multi-organisation steering group met over a year to redesign the pathway and develop new or modify old tools to improve care.

A ‘cause for concern’ trigger tool was adopted by community heart failure nurses to identify patients with advanced disease to promote earlier recognition of patients who could benefit from a shared palliative approach (see Appendix 2). Patients are then discussed and management plans made at a monthly Integrated Advanced Heart Failure Forum (AHFF) in the hospital. Decisions made at the AHFF are communicated to the GP and other consultant teams involved. Monthly peer support meetings are provided for cross discipline nurse specialists.

Joint working has allowed trialling of new shared tools to support a palliative approach including the end of life care folder with advance care plans in the patient's house, the London Ambulance Service protocol for palliative patients with its symptomatic treatment guide and referral to community services rather than hospital transfer.

Important outcomes include:

- adoption of terminology to “Follow a Palliative Approach” introduced into Cardiologist letters
- increased access to specialist palliative care services
- advance care planning
- death outside hospital
- community heart failure nurses reported improved job satisfaction.
Summary

- Hospice care has strengths and attributes that could contribute valuable care for people with heart failure throughout the disease trajectory according to need.

- Its focus on advanced, progressive illness and bereavement could augment care alongside that provided by other health and social care professionals.

- Hospice staff can help identify when someone is approaching the end of life, engage in difficult discussions about future priorities and offer highly effective palliation of symptoms that are common and distressing.

- Care is person-centred. This is a key driver in encouraging hospices to extend their care on a personal needs basis rather than a diagnosis basis.

- The innovation and pioneering spirit of hospices means they are ideally positioned to lead on new developments in care to meet the unique needs of people with heart failure, their families and carers.

- When hospices are well integrated in their local health and social care systems they can be highly effective facilitators of palliative care.

- Hospices are renowned for their education and training. Mutual improvements in knowledge and skills will result when this is provided in a reciprocal manner with providers of heart failure care.

- Hospices engage with their communities and can call on the time and expertise of local people, to encourage volunteering to support more people in their own homes, living with heart failure.

- 60% of people with heart failure struggle with leisure and hobbies^25

- 40% of people with heart failure struggle with routine daily activities^25
Section 4. First steps for action

Through a carer’s lens: Shirley’s story

The first time we were involved with the Hospice of St Francis was in 2010, when my husband Fred was admitted, as everyone thought he was dying. He had his defibrillator turned off and we were prepared for the worst. To our surprise, he improved and came home. The hospice nurse supported us at our home along with regular consultant appointments at the hospice. He was so much better that his defibrillator was switched back on again!

After two years, we stopped using the hospice as we felt someone else could benefit from the care, and we knew we could get in touch with the hospice when we needed. This time came in May 2016 when his condition became worse … it was time to call the hospice.

Although Fred was very frightened and fretful, to our great relief as soon as we got him to the hospice, he started to calm down. Fred spent nine days at the hospice. Before he died, the doctors explained everything. They didn’t mind how many times we asked. They looked after us, particularly me as I stayed with Fred. We could open the doors to his room so our young grandchildren could play outside on the grass.

On the day of Fred’s passing, the nurses said that the time was close and to inform the family. The staff didn’t mind that there were a lot of us. After Fred died, we spent two hours with him. The staff let the family say their goodbyes even though it was late at night. We will always be so grateful for that. The hospice staff still keep in touch with me.

Hospice-enabled care for people with heart failure

Hospice-enabled care for people with a diagnosis of advancing heart failure can benefit patients, their families and carers. In order to deliver this, hospice leaders will need to assess their organisational readiness, current practice and local relationships.

First steps for hospices to develop a hospice-enabled heart failure service

1. A corporate commitment to developing hospice heart failure services, and assessment of organisational readiness.

2. Understand local unmet need and develop outcomes that measure the effectiveness of addressing need.

3. Collaborative and creative approaches to adapt existing service models based on metrics of local need.

4. Evidence-based approach – using national evidence and existing practice examples, evaluating from the start of any new service.

5. Development and support of staff and volunteer workforce.
1. A corporate commitment to support people and those close to them affected by advanced heart failure

Development of new heart failure services by the hospice needs commitment from the board of trustees, captured in strategic and operational plans so that progress can be monitored and resources (time, money, people) allocated for capacity building, consultation and marketing of new services. Establishing heart failure champions at board, senior management and clinical levels will be helpful. Their role is to help identify and lead on heart failure initiatives, ensuring that heart failure related care remains embedded in hospice plans, and any barriers to care are identified and addressed.

**Checklist:**

- Is there a strategic and operational commitment from the board and executive team to take forward the heart failure agenda?
- Is your vision of hospice-enabled heart failure care shared by the staff team, volunteers, carers and patients?
- Are there resources (time, money, people) allocated to support the plans?
- Do you know the current needs of those people living with heart failure in your catchment?

2. Strategy should be based on understanding of local unmet need for heart failure patients

**Understand your local demography** – collect prevalence and death data relating to heart failure from the Joint Strategic Needs Assessment, local public health departments as well as data collected by local cardiology services and the CCG.

**Understand the needs of those living with heart failure and how the hospice team can help** – symptom prevalence, family support, coordination needs, advance care planning and care of the dying.

**Conduct a gap analysis** to assess what a new service might address and how it might be best configured.

Key metrics in your catchment area for people with heart failure include:

- numbers of people in local population currently living with heart failure
- place of death of heart failure patients in your catchment
- of patients who died, how many days were spent in hospital in their last 90 days?
3. A collaborative and creative approach to adapting existing models of care and development of new services in response to identified needs

A collaborative approach can begin with education, support and training for non-palliative health professionals who will then be able to manage the vast majority of palliative care needs of their patients. In turn, the cardiology and primary care teams can support, educate and train the hospice staff, to equip them to care for this group of patients. This mutual respect will form a strong basis for future partnerships.

The triggers for referral need to be widely agreed, accepting that the unpredictable decline of patients should not be a barrier to referral. Need rather than prognosis should be the underpinning ethos, with a focus on realistic goals.

The most successful innovations to date are multi-agency in nature and involve ongoing dialogue with users of the service. Hospices must recognise they are a small element of care and that direct involvement in patient care is often neither necessary nor sustainable; they can however make a significant contribution at the right time, with skill-sharing. Hospices often have models of 24 hour access to advice for families and carers – these services can support those living and dying with heart failure.

Checklist:

- What links do you have with current providers of heart failure services in your locality? Could you be engaged as co-designers of new services?
- Have you explored or are you aware of how other hospices are contributing to the heart failure agenda? Could you adopt or replicate any of these approaches?
- Can your hospice services for carers extend to carers of those living with heart failure?
- What barriers do people with heart failure and their carers face when wanting to access services from your service?

4. An evidence-based approach to care

Heart failure palliative care has a growing body of evidence about what is effective and best practice. Hospices need to become familiar with this body of literature and consider its application to their strategy.

Hospice care is generally highly evaluated by users of the service – identifying the specific ingredients that can be ‘injected’ into other settings in order to make a difference to more people living and dying with illnesses other than cancer is a key challenge for the sector.

Seek opportunities to build the current body of knowledge by evaluating your new services from the start, agreeing outcome metrics and economic indices.
5. **Investment in the development and support of hospice staff and volunteer workforce**

It is essential for hospice staff and volunteers to understand and be confident in enabling access and support for those with heart failure. They need to understand the need, the rationale and the service. A heart failure project group may be one way to provide in-house learning and ownership of developing practice.

Joint education sessions with the primary care and cardiology teams will act as a good catalyst for learning, developing the important relationships and understanding of each other’s approach.

The increasing use in hospice care of clinical outcome metrics, such as IPOS and Phase of Illness, should make the individual and organisational impact of new heart failure services easier to evaluate.

**Checklist:**

- How are you building awareness, knowledge, skills and confidence throughout the organisation to support your heart failure project?
- How are you marketing your new heart failure services to referrers?
- Do you offer shadow placements for heart failure clinicians?
- Where do you access your heart failure training?

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48% of cancer patients are on the GP palliative care register

7% of heart failure patients are on the GP palliative care register\(^6\)

30-40% with advanced heart failure die within a year\(^28\)
Conclusions

Hospices have much to offer people living with and dying from heart failure, their families and friends and other healthcare professionals involved in their care.

Historical barriers are starting to give way in the face of increasing need and strong patient voices calling for improved access to patient-centred care and palliative care services. However, much is still to be done.

The use of an integrated care model appears to be the best fit in terms of appropriateness and sustainability, allowing the right care for the right person by the right professional at the right time. Such an approach prevents hospice services being overwhelmed.

Hospice-enabled care allows the other health professionals involved in the person’s care to develop generalist palliative care skills including those of identification and triage, thus fostering good care for all patients, while preventing an unsustainable dependence on specialist palliative care. Cardiology-supported care allows patients to be cared for safely in hospice services while still receiving optimised cardiac care.

Palliative care input can reduce heart failure re-admissions by 42%.

42%
Appendix 1: Caring together: Medical Anticipatory Care Plan

Caring Together Programme

Caring Together Medical Anticipatory Care Plan Summary

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<th>Patient Details:</th>
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<td>DOB/CHI:</td>
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NOK/Main Carer Details: (please insert both if NOK is different from main carer)

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Power of Attorney/Guardianship Insitu: Yes/No

Diagnosis: ADVANCED HEART FAILURE

Priorities of Care:

1. Current Place of Care: Home/Hospital/Hospice/Care/Nursing Home/Other
2. Preferred place of care: Home/Hospital/Hospice/Care/Nursing Home/Other
3. Preferred place of death: Home/Hospital/Hospice/Care/Nursing Home/Other

Resuscitation Status:

Cardiac Device Status: Active/Deactivated/Not Applicable

Ceiling of Therapy: ITU etc with Yes/No

Consultant: Care Manager:

Professional Services to be considered if condition or situation changes:

1. Name: Contact Details: 
2. Name: Contact Details: 

Emergency contact details
Cardiology
Palliative care
Cardiac Physiology (Mon-Friday 9-5)

NB: A detailed summary of the key components of this Medical ACP summary are contained within the attached Medical Anticipatory Care Plan.

Date Completed: Review Date:

NAME CHI
### Caring Together Medical Anticipatory Care Plan

**Patient and Main Carer Details**

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<th>NOK Details (Relationship):</th>
<th>Main Carer Details (Relationship):</th>
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**Care Manager Details:**

**Diagnosis List:**

**Current Medications:**

**Changes to medications**

**Medications to stop:**

**Medication intolerance:**

**Device details:** Applicable / Not applicable

**Medical and Symptom Management Considerations:**
## Caring Together: Medical Anticipatory Care Plan

### Priorities of Care

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<th>Current Place of Care:</th>
<th>Preferred place of care:</th>
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### Device Status if appropriate:

DNA / CPR Status:

Intensive Care Referral: Not Appropriate

Central line access: Not Appropriate

Appropriate maximal medical therapy:

- Inta-aortic Balloon Pump (IABP): YES / NO
- IV Inotropes: YES / NO
- IV Diuretics: YES / NO
- SC Diuretics: YES / NO
- Oral medications: YES / NO

Transfer to hospital in the event of acute deterioration: Avoid if at all possible

### Key Professional Services Currently Involved:

- NAME - Consultant Cardiologist GRI
- NAME – Care manager
- NAME - GP
- NAME - Other Consultant

### Key Professional Services to be considered if condition or situation changes:

### Significant Conversations

Patients Understanding of current situation:

Carers Understanding of current situation:

### Helpful/Emergency Contact Numbers:

- Cardiology GRI: ..........................
- HFLN: ..........................
- DN: ..........................

NAME CHI
Caring Together: Medical Anticipatory Care Plan

### Consent
Has patient agreed to sharing their personal details with other professionals (including for use in ePCS and KIS):

<p>| | | |</p>
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<thead>
<tr>
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<tr>
<td>Yes</td>
<td>No</td>
<td>NA</td>
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</table>

Has carer agreed to sharing their personal details with other professionals:

<p>| | | |</p>
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<tr>
<td>Yes</td>
<td>No</td>
<td>NA</td>
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</table>

Has next of kin agreed to sharing their personal details with other professionals:

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<tbody>
<tr>
<td>Yes</td>
<td>No</td>
<td>NA</td>
</tr>
</tbody>
</table>

### This Medical ACP has been agreed by:

**Consultant Cardiologist (Dr Karen J Hogg)**

Signature: 

Date: 

Care Manager (Print Name):

Signature: 

Date: 

All components of this Medical ACP have been discussed and agreed with the patient and family members (where applicable).

**Date Completed:**

**Review Date:** Weekly Recommend as appropriate

---

**This patient has attended a heart failure and supportive care clinic.**

**This patient has met the criteria for Caring Together and should be considered for entry onto the appropriate palliative care registers**

<table>
<thead>
<tr>
<th>For further information on the Caring Together Programme:</th>
<th>Developed from previous work undertaken as part of British Heart Foundation heart failure palliative care project: the Glasgow and Clyde experience (2006-2010).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Telephone: 0141 557 7552</td>
<td>Copyright © Caring Together Programme 2014. Caring Together Programme comprises Marie Curie Cancer Care, the British Heart Foundation, NHS Greater Glasgow and Clyde and Glasgow Caledonian University. This document may be reproduced without amendment by third parties subject to this copyright notice being reproduced in full.</td>
</tr>
<tr>
<td>Email: <a href="mailto:caringtogether@mariecurie.org.uk">caringtogether@mariecurie.org.uk</a></td>
<td>Marie Curie Cancer Care. Registered as a charity in Scotland (no. SC038731) and in England and Wales (no. 207994) British Heart Foundation. Registered as a charity in Scotland (no. SC039426) and in England and Wales (no. 225971)</td>
</tr>
</tbody>
</table>

Pub. date: April 2011

Review date: November 2014

Issue No: 05

Author: Caring Together Programme Team

www.mariecurie.org.uk/caringtogether

www.bhf.org.uk/caringtogether

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**NAME**

**CHI**
Appendix 2: Trigger tool to recognise need for a shared palliative approach

The aim of the trigger tool is to help the clinician identify those patients who may be entering the final stages of heart failure. If the patient meets two or more of the following criteria the clinician should consider discussing the patient at the multi-disciplinary team meeting.

### Specific chronic heart failure triggers

<table>
<thead>
<tr>
<th>Specific chronic heart failure triggers</th>
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</thead>
<tbody>
<tr>
<td>The patient with advanced disease makes a choice for comfort care only, not curative treatment.</td>
</tr>
<tr>
<td>Three admissions within the past year with symptoms of heart failure.</td>
</tr>
<tr>
<td>New York Heart Association Class III or IV: short of breath at rest or on minimal exertion despite maximal medical therapy.</td>
</tr>
<tr>
<td>Difficult physical or psychological symptoms despite maximal medical therapy.</td>
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</table>

### General predictors of end stage illness

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<th>General predictors of end stage illness</th>
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<tr>
<td>Weight loss – greater than 10 per cent weight loss over past six months.</td>
</tr>
<tr>
<td>General physical decline.</td>
</tr>
<tr>
<td>Serum albumin &lt;25G/L.</td>
</tr>
</tbody>
</table>

Used with permission from St Luke’s Hospice, Harrow and Brent
Resources

The following resources aim to help hospices achieve high quality care for people with heart failure, their families and carers.

**General heart failure information (including organisations)**

**British Heart Foundation**
A huge resource with information and practical resources for all aspects of heart disease, including heart failure.

**Heart Failure Matters**
A new website with excellent heart failure resources for patients and professionals
www.heartfailurematters.org

**British Society for Heart Failure**
Website lists support organisations, patient groups and links to information:
www.bsh.org.uk/patients/organisations

**Hospice UK**
Information on all aspects of hospice and palliative care, including links to publications, conference slides, resilience and carer resources: www.hospiceuk.org

**Age UK**
General information and advice on finances, capacity and other legal issues:
www.ageuk.org.uk

**NHS Choices**
Online facility to find heart failure services according to postcode or town:
www.nhs.uk/Service-Search/Heart%20Failure/LocationSearch/55

**APPG Focus on Heart Failure**

**National Council for Palliative Care (NCPC)**
Offers heart failure-specific publications and events news: www.ncpc.org.uk

**Vision, strategic planning, commissioning and partnership working**

**European Association for Palliative Care (EAPC)**
General information and publications, includes link to EAPC and Heart Failure Association of European Cardiac Society Joint Task Force on Palliative Care for People with Heart Disease:
www.eapcnet.eu/Themes/SpecificGroups/HeartDisease.aspx

**Dying Matters**
General information on death and dying: www.dyingmatters.org

**Hospice UK Commission into the Future of Hospice Care**
www.hospiceuk.org/what-we-offer/commission-into-the-future-of-hospice-care
Personal experiences
British Heart Foundation
Audio visual links to stories from people living with heart disease: www.bhf.org.uk/community/your-stories

Heart Matters Magazine
www.bhf.org.uk/heart-matters-magazine

Difficult Conversations
British Heart Foundation publication written in collaboration with the National Council of Palliative Care, includes conversations with over 60 people affected by heart failure: www.bhf.org.uk/publications/living-with-a-heart-condition/difficult-conversations---talking-to-people-with-heart-failure-about-the-end-of-life
www.ncpc.org.uk/publication/difficult-conversations-heart-failure

Healthtalk.org
Online resource which provides free, reliable information about health issues, by sharing people’s real-life experiences: www.healthtalk.org/home

Care specific resources
British Heart Foundation
ICD deactivation at the end of life: principles and practice.

Gold Standards Framework (GSF)
Provider of training in end of life care for generalist frontline staff: www.goldstandardsframework.org.uk/home

Supportive and Palliative Care Indicators Tool
Prognostic indicator guideline developed in Edinburgh (alternative to GSF above). www.spict.org.uk

Education and training for all levels of staff
British Society of Heart Failure
Offers a range of courses: www.bsh.org.uk/resources/courses

Developing end of life care practice

Difficult Conversations
See above.

E-learning for Healthcare
Includes modules on end of life care for all, shared decision making, and personalised care planning: www.e-lfh.org.uk/home
Heart failure friendly environments

Housing Learning and Improvement Network
Guides to buildings and environments friendly for a number of conditions.
www.housinglin.org.uk

Health guides

Map of medicine
http://mapofmedicine.com

National End of life Care Intelligence Network
General demographic information and heart failure statistics.
www.endolifecare-intelligence.org.uk/home

National Institute for Health and Care Excellence (NICE)
Everything NICE has produced on the topic of heart failure is available on these sites, eg related guidelines, NICE Pathways, quality standards and advice: www.nice.org.uk
www.nice.org.uk/guidance/qs9

Primary Care Web
An NHS mail address is needed to access this site, but restricted access will be granted to non NHS organisations such as hospices: www.primarycare.nhs.uk

Palliative Care Symptom Guide

Other references and resources


Wingate S, Bain KT, Goodlin SJ. Availability of data when heart failure patients are admitted to hospice. Congest Heart Fail 2011;17(6):303-8.
References


18. Wong FK, Ng AY, Lee PH, Lam PT, Ng JS, Ng NH, Sham MM. Effects of a transitional palliative care model on patients with end-stage heart failure: a randomised controlled trial. Heart 2016.


