End of life care in heart failure
A framework for implementation
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Foreword

In recent years, we have made enormous strides in our understanding of heart disease. We have a wealth of evidence on what care and treatment approaches work, the role of new interventions to improve the outcomes for patients and the quality of services. Consequently, many people with heart disease are now living longer, more productive and more comfortable lives. We have also seen great strides in the consistency of care, thanks to the clinical framework that has underpinned and driven the changes.

While we celebrate this success, we should also acknowledge that heart disease remains the second biggest killer in England. It is also changing its profile; people with heart disease are older with more long-term care needs. This requires a different approach to ensure that the high quality care we have come to expect elsewhere is available at the end of peoples’ lives.

Though cancer patients have until recently been the focus of much of the expertise developed by hospices and specialist palliative care services, the National End of Life Care Strategy aims to ensure provision of expert end of life care moves beyond this, to include all those with life limiting conditions in all care settings. Commissioning end of life care for heart failure patients is particularly challenging. Progression of heart failure is variable and unpredictable, the population often have multiple, and complex needs.

For some years the Heart Improvement Programme have been in the vanguard of promoting supportive and palliative care for people with heart failure and this framework has been developed in collaboration with members of the National End of Life Care Programme. It aims to help commissioners to understand the complex care environment in which people with heart failure live and ensure the NHS can deliver sufficiently flexible and responsive services to meet their needs.

We recommend this document to you.

Professor Roger Boyle
National Director for Heart Disease and Stroke

Professor Sir Mike Richards
National Clinical Director for Cancer
Introduction
In 2008, the National End of life Care Programme published Information for Commissioning End of Life Care which comprehensively described the issues relevant to commissioning the complex service provision of general end of life care. Of necessity, that publication offered a relatively generic approach. This document, *End of life care in heart failure - a framework for implementation*, sets out to raise awareness of the supportive and palliative care needs of people living or dying with progressive heart failure, to facilitate the commissioning of services specifically tailored to meet those needs. It does so in the context of the End of Life Strategy which aims to ensure that all adults receive high quality care at the end of life, regardless of their age, place of care or underlying diagnosis.

The burden of heart failure
Heart failure is a complex clinical syndrome causing patients to experience breathlessness, fatigue and fluid retention due to functional or structural cardiac abnormalities. The National Service Framework for Coronary Heart Disease described heart failure as the final common pathway for the many cardiac conditions that affect heart pump function, with coronary artery disease and high blood pressure as the most common antecedent conditions.

Although the increasingly successful management of these diseases, particularly intervention for heart attacks, has improved survival, the trade off lies in a burgeoning clinical cohort living with left ventricular dysfunction. Heart failure is now the only cardiovascular disease increasing in prevalence. In the United Kingdom, heart failure affects about 900,000 people with 60,000 new cases annually, and is predominantly a disease of older people with all their attendant comorbidities. At least 5% of those aged over 75 years are affected, rising to about 15% in the very old. Given the relative ageing of the general population, those with heart failure will continue to consume a major and increasing proportion of clinical and public health resources. Heart failure is a high cost Healthcare Resource Group (HRG) and multiple hospital admissions, a common feature of advanced heart failure, account for a significant amount of this health care expenditure. For the year 2007-2008, there were almost 60,000 admissions with heart failure in England and Wales, requiring more that 750,000 bed days. Some of these admissions might be avoided with anticipatory care planning and the provision of community health and social care support.

Despite therapeutic advances, heart failure remains a progressive, incurable and ultimately fatal long term condition which has a major effect on affected individuals and their families. The symptomatic burden and mortality risks are similar to common cancers and of all general medical conditions heart failure has the greatest impact on quality of life. Despite a growing recognition of the requirement to provide supportive and palliative care for this clinical cohort, the recent National Heart Failure Audit demonstrated continuing significant unmet needs: only 6% of those dying with heart failure were referred to palliative care. Several factors may contribute to this paucity of support but this often results from prognostic uncertainty and difficulties in defining end-stage heart failure, as evident in the heart failure disease trajectory.
The heart failure disease trajectory

Central to commissioning a high quality, cost effective service is a better understanding of the nature of advanced heart failure and, in particular, the end of life phase.

As described below, the trajectory of heart failure is comparable to clinical populations with other forms of progressive organ failure such as chronic obstructive pulmonary disease and even to some cancers. However, the course of heart failure is exceptional in its unpredictability, and for an individual patient, no specific trajectory can be reliably anticipated.

A representative disease trajectory for heart failure is shown diagrammatically in Figure 1. Typically five phases may evolve.

Phase 1 represents symptom onset, diagnosis and initiation of medical treatment. This often occurs as the patient is admitted to hospital with a life-threatening episode of breathlessness. Some patients may die at this point. However, for other patients the onset of symptoms is more gradual, and they may present to the general practitioner (GP) with slowly progressive fluid retention and/or breathlessness. With either presentation, once the diagnosis is confirmed, treating the patient with drug therapy, combined with cardiac surgery if required, will often produce a dramatic improvement in symptoms. In the initial stage patients and carers need education on the nature of heart failure, the treatment options, and advice on diet and fluid management. Patients usually now enter a plateau period of variable duration, sometimes lasting several years.
**Phase 2** - During this period, in which patients generally remain under the care of their GP, they should be advised how to monitor their condition at home and when to call for help. Ongoing support and education for patients and their carers promote autonomy, self care, adherence to therapy and a reduction in the risk of inappropriate admission. Because life expectancy is so difficult to predict and patients feel relatively well, most clinicians are reluctant to talk to patients or carers about prognosis at this time.

**Phase 3** occurs when patients develop periods of instability with recurrence of symptoms linked to deterioration in heart function. Rebalancing of treatment may restore stability, but often a new approach is required with the use of implantable cardiac devices to improve heart pump performance (cardiac resynchronization therapy) or to shock the heart back to normal rhythm (implantable cardioverter defibrillator (ICD)) in the event of a life-threatening arrhythmia. Increased patient and carer support is required here, and there is a major role for community heart failure nurses. Regular review including home visits may help to avoid unnecessary hospital admissions.

As functional deterioration continues, **Phase 4** is marked by the patient experiencing increasing symptoms and exhibiting declining physical capacity, despite optimal therapy. Consideration for other treatment options such as cardiac transplantation may be considered in this phase. Judging the right time to discuss prognosis and advance care planning with a patient can be very difficult, but the reappearance of symptoms in phases 3 and 4 and raising the question of the possible need for aggressive intervention often present an opportunity to initiate discussion.

The course of heart failure and the time spent progressing through these illness phases is very variable and it is important to emphasise that clinical deterioration and death may occur at any time (Appendix C). However, as shown (Box 1), clinical features often become evident suggesting that the situation is irrecoverable when formal end of life care is required.

**Phase 5.** Goals of care need to be openly reviewed with the treatment emphasis shifting to the management of symptoms rather than the futile continuation of therapy offered only for prognostic benefit. Formal assessment of supportive and palliative care needs is required at this time and specialist palliative care may need to be involved. Multi-organ failure is the usual terminal mechanism in Phase 5, whereas sudden arrhythmic cardiac death is more common in earlier phases. Review of resuscitation status and reprogramming of cardiac devices may be important management issues. Deactivation of ICDs is frequently left almost to the point of death when agonal arrhythmias may trigger device discharges, disturbing the patient and distressing the family. When the patient enters the terminal phase, the situation often progresses rapidly, and unless treatment policies have been defined in advance, care may become disorganised.

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### BOX 1

**Poor prognosis is likely in heart failure patients:**

- of advanced age
- with refractory symptoms despite optimal therapy
- who have had at least three hospital admissions with decompensation in less than six months
- who are dependent for more than three activities of daily living
- with cardiac cachexia
- with resistant hyponatraemia
- with serum albumen of less than 25g/l
- who experience multiple shocks from their device
- with a comorbidity conferring a poor prognosis, such as terminal cancer
Advance Care Planning

Advance care planning allows the patient to record their wishes for care prospectively against the possibility of later clinical events limiting their ability to engage meaningfully in decision making or communication relevant to their future healthcare.

Forms of advance care planning include an advance statement, advance decision to refuse treatment (ADRT), and lasting power of attorney (LPA). In appointing a LPA, the patient assigns authority to another individual to contribute to decisions on treatment if capacity is later lost. The LPA requires to be registered with the Office of the Public Guardian.

While not legally binding, advance statements must be taken into account by those making proxy decisions in the patient’s best interest. In contrast, ADRT and LPA are legally binding if properly formulated and recorded when the patient has capacity. All forms of advance care planning may inform decisions by clinicians on the policy for cardiopulmonary resuscitation.

As outlined in the recently published guidance from the General Medical Council, judging when and how to discuss changes in treatment emphasis, goals of care and advance care planning with a patient is difficult and often it is left too late12. Heart failure specialists have only recently started to engage in this practice13. The resources highlighted may help to facilitate this process. Commissioners should encourage providers to develop advance care planning, and it is important that such decisions are fully informed, regularly reviewed, properly recorded and accessible to providers across all care sectors.

Useful resources:


Multidisciplinary working

Figure 2 shows the core elements required of the necessary multidisciplinary team (MDT) approach to care provision for those with progressive heart failure.

This service model requires contributions from a broad range of social and health service sectors and good care coordination is necessary to avoid fragmentation. Personalisation of care is central; the relative importance of the different components will be unique to each patient and their families and will vary in intensity over the course of the illness. Commissioners will need to ensure service specifications enable services that can be tailored to the needs of individual patients and their carers and responsive to changes in those needs.

Commissioning of services through a single point of contact may mitigate some of this risk. Successful provision of social care support to the carers of patients with end-stage heart failure has been developed in the Care-Plus project, sponsored by the King’s Fund, in the London Borough of Tower Hamlets (www.carerscentre.towerhamlets.org.uk).

Funding streams for clinical, social care and voluntary sector providers are often discrete. Consequently, effective commissioning requires partnership working between the NHS, social services and their local partners who are significantly involved in end of life care. A Joint Strategic Needs Assessment, which is a statutory responsibility of the primary care trust (PCT) and local authority, should establish a shared evidence-based consensus on key local priorities and facilitate whole system care. In addition, the National Council for Palliative Care has produced a population-based needs assessment for palliative and end of life care, a national data set to inform commissioners of the needs of their local populations, including those dying of cardiovascular diseases such as heart failure17.

Transition between different care settings presents particular organisational hazards. At times it can be difficult to ascertain where responsibility for care sits, the health service or local authorities and deficiencies and inequities in social service provision for older people with heart failure have been emphasised15, 16.
What is end of life care in heart failure?

As shown below, the National Council for Palliative Care has described the features of end of life care[18].

‘End of life care is care that helps all those with advanced, progressive and incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.’

Palliative care providers are expert in holistic assessment and intervention to attend to the needs of patients and their families. There is a clear role for specialist palliative care in the terminal phase of heart failure and this may be provided in hospices or hospital based departments or on a consultancy basis in the community. There are several examples of professional collaboration between specialist palliative care and cardiologists[19]. However, much general palliative care and supportive care can be provided by the GP, community or heart failure specialist nurses. A British Heart Foundation (BHF) initiative exploring the potential impact of developing a specialist heart failure nursing service with enhanced palliative care skills is currently being evaluated. Heart failure specialist nurses are increasingly working with palliative care services and may be ideally placed to act as care coordinators as proposed in Figure 2[20]. Collaboration between the BHF and Marie Curie Cancer Care in the Better Together programme has been shown to benefit the care of advanced heart failure patients in the community[21]. Economic analysis of the Marie Curie Delivering Choice programme in Lincolnshire, where local service reconfiguration successfully accommodated patients’ wishes to die at home, showed this to be cost neutral[22]. In this project, 77% of the service users had cancer and, as proposed in the National Audit Office review of end of life care, developing similar service structures for non-cancer patients such as those with heart failure, are likely to be cost saving given their greater utilisation of acute services[23].

End of life care should be available in all places of care be it the patient’s home, a care home, hospice or hospital - including coronary care units where many heart failure patients are admitted. All of the tools highlighted in the End of Life Care Strategy - such as the Liverpool Care Pathway, the Gold Standards Framework, and the Preferred Priorities for Care - are applicable to heart failure patients, and should be available in all care settings. These are described fully in the End of life Care Strategy document which also provides a basis for an integrated approach to commissioning[2]. The End of Life Care Strategy is shown in schematic form in Figure 3.

Useful links:
www.endoflifeareforadults.nhs.uk
www.endoflifecare-intelligence.org.uk
Figure 3. In the End of life Care Strategy, a whole system care pathway is proposed as a model for commissioning integrated end of life care services

**STEP 1**
Discussions as the end of life approaches
- Open, honest communication
- Identifying triggers for discussion

**STEP 2**
Assessment, care planning and review
- Agreed care plan and regular review of needs and preferences
- Assessing needs of carers

**STEP 3**
Coordination of care
- Strategic coordination
- Coordination of individual patient care
- Rapid response services

**STEP 4**
Delivery of high quality services in different settings
- High quality care provision in all settings
- Acute hospitals, community, care homes, hospices, community hospitals, prisons, secure hospitals and hostels
- Ambulance services

**STEP 5**
Care in the last days of life
- Identification of the dying phase
- Review of needs and preferences for place of death
- Support for both patient and carer
- Recognition of wishes regarding resuscitation and organ donation

**STEP 6**
Care after death
- Recognition that end of life care does not stop at the point of death.
- Timely verification and certification of death or referral to coroner
- Care and support of carer and family, including emotional and practical bereavement support

Adapted from the pathway, National End of Life Care Strategy (2008)
Discussions as end of life approaches

‘Effective communication between patients and clinicians is fundamental. We know patients and their carers value it highly. We also know it is sometimes poor.’

Professor Sir Mike Richards

Specific issues in heart failure

- The treatment of confirmed heart failure favours a guideline driven medical model. Clinicians need to explore and address health and social care issues often more relevant to the needs of patients and their carers and look beyond the specific remit of heart failure.\(^{24}\)
- Clinicians, including heart failure personnel, are reluctant to embark on discussions about end of life issues in the face of prognostic uncertainty and a perception of implied professional failure. There may also be a fear of upsetting patients or carers.
- Prognostic tools (‘trigger tools’) can help to identify patients who are entering the end of life phase of their illness. Once this point is reached, the patient should be part of a discussion within the MDT to confirm that treatment has been optimised, to reassess goals of care and to ensure that information relating to a change of emphasis to symptomatic care is appropriate and disseminated to all those involved with the patient. Generic community based palliative care should be enabled and specialist palliative care involvement may be helpful. The patient and family should also be informed of the results of such deliberation and if possible contribute to this process with recording of their needs and preferences.
- Patients would prefer doctors to open this dialogue but this rarely occurs. Few heart failure specialists have been trained to conduct these difficult conversations. The person delegated to discuss end of life care with the patient should have had this training, be someone familiar to the patient and be in a position of professional trust. Heart failure nurses may be ideally placed to broach this difficult subject in conjunction with the GP.
- Patients and carers may still have little insight into the significance and implications of the diagnosis of ‘heart failure’. Others may have been informed but prefer not to know. Some may be disempowered by the highly technical nature of the assessment and treatment of the condition. Cognitive impairment is also common in those suffering from heart failure, impacting upon mental capacity.\(^{25}\)
‘Your symptoms may settle as we adjust the medication. If they do not, you may want to discuss how you are managing and what support you and your carers might need.” “You may want to discuss these issues with me or with the heart failure nurse… perhaps you might discuss your questions, concerns and priorities with your family.’

**Key messages for commissioners**
- Service providers should agree locally on prognostic signs / indicators which can be used as a means of identifying which patients are approaching end of life (see Box 1).
- Service specification should include investment in communication skills training for heart failure specialists designated to undertake these challenging discussions.
- Ensure effective mechanisms are in place to facilitate information exchange across all care sectors.

The importance of a MDT approach in deciding when a patient is reaching the end of life was highlighted at an advisory group meeting. It is also important to plan ongoing care in this way and it was proposed that **ALL** health professionals involved in communicating with patients or involved with the care of patients reaching the end of life should be trained in advanced communication skills.
Assessment, care planning and review

Specific issues in heart failure

- In the last year of life there is compression of illness and people with advanced heart failure often have multiple crises admissions, frequently with little contact between the admitting team and the heart failure service.
- Currently, heart failure care is often fragmented with a lack of clarity about who should assess, plan and review needs in a holistic way. A MDT based care provides a model for cross sector collaboration but is time constrained and not universally applied. Specialist palliative care may be involved too late in this process.
- Lack of consensus about how to assess the broader, supportive care needs of heart failure patients and their informal carers as these evolve and goals of care change. This impacts on anticipatory end of life care planning, including appropriate modification of drug and device therapy, and undermines patient autonomy in maintaining preferences for place of care and death. About 90% of the last year of life is spent at home yet 59% of patients die in hospital.

- To date, the cardiology workforce has not engaged significantly in formal advance care planning.
- There is a lack of cohesion between primary care, secondary care and social care providers.
- At present, no favoured model of information recording or exchange is applicable to multiple agencies.
Key messages for commissioners

- Vertical integration between community and secondary care providers might promote better care coordination and cost saving.
- Proactively identifying heart failure patients likely to be in the last year of life would enable such patients and their carers to benefit from established programmes such as the Gold Standards Framework and the Preferred Priorities for Care.
- Advance care planning should be endorsed.

People with many symptoms often benefit from a full re-assessment from the GP and district nurse services. This includes checking out the concerns of the patient and their carers, asking about what the patient or carer wants or needs in terms of help. Financial and social (practical) helping services, emotional support services may become important at this point.

‘Because your heart failure has been unstable recently, I suspect that I should be discussing with your GP how the next period of time might pan out. Do you have concerns or questions about what this period of unstable health could mean for you?’
Coordination of care

Specific issues in heart failure
- Increasingly, patients with severe heart failure are managed in the community by specialist heart failure nurses, and their input is crucial. They are in the best position to detect early signs that the condition is worsening and to act to prevent acute exacerbations.
- Specialist nurses cannot cover 24/7 and as the condition deteriorates, more generic out of hours services provided by community nurses and/or ambulance services may be called upon. The relationship between these elements of the service, the patient’s GP and the hospital services is pivotal.
- Because a variety of healthcare professionals may be involved in an individual patient’s care, it is important that the patient’s care plan, multidisciplinary record, advance care plan and any other relevant documentation are available and accessible in that patient’s home.
- Patients with heart failure commonly miss out on the advantages models of care coordination such as the Gold Standards Framework provide because they are rarely identified as being suitable to be placed on a ‘supportive care register’ in primary care.

BOX 2
A heart failure patient’s wish to die at home may be thwarted by:
- Insufficient anticipation of expected symptoms
- Uncertain or poorly documented preferences and priorities for care
- A lack of discussion with family and carers prior to the terminal deterioration
- Exhaustion or fear amongst family / carers
- Hypoxia, leading to confusion and distress: this can trigger families or health professionals to call an ambulance
- Inadequate collaboration with ‘out of hours’ medical and nursing services
- The need for intravenous diuretic therapy.

- The quality of care available in the home at this point is central to management of symptoms and respecting the wishes of the patient. When patients with heart failure deteriorate it is frightening for them and their carers and they tend to end up in hospital.
Key messages for commissioners

- Appointing a single point of contact to coordinate care and access support may significantly improve care navigation.
- Established mechanisms for care coordination at the end of life disproportionately favour cancer patients, but many of the same processes can be adapted for heart failure patients.
- Specialist heart failure nurses are in an ideal position to act as care coordinators. The use of these nurses has already been shown to improve care cohesion, engender better clinical outcomes, and reduce admission rates with demonstrable cost savings\[^{7}\].

‘If a person is likely to live for a matter of weeks, days matter. If the prognosis is measured in days, hours matter. PCTs and LAs will wish to consider how to ensure that medical, nursing and personal care and carer’s support services can be made available in the community 24/7’

End of Life Care Strategy (2008)
End of life care in heart failure: A framework for implementation

Delivery of high quality services

**Specific issues in heart failure**

- In advanced heart failure, patients are likely to benefit from specialist cardiology review: symptoms of breathlessness and fatigue can sometimes be improved with adjustment of medication or device therapy.
- Once patients have been deemed to have reached the end of life stage, the discussion about appropriate care and place of care should take place if not already undertaken.
- As the illness progresses specialist heart failure care will need to be complemented by a range of other services.
- Health and social care staff who are inexperienced in dealing with heart failure (for example district nurses, out of hours services, palliative care services) will require guidance or training to identify any reversible precipitants of symptomatic deterioration. Joint working may be helpful.
- Symptom management in advanced heart failure is complicated by both cardiac and renal factors. Multi-specialist input may be beneficial.

**BOX 3**

**Patients with advanced heart failure and their carers may need access to several of the following services:**

- Primary care services - District nursing services
- Psychological support services - Acute medical services - Specialist palliative care services
- Out of hours services - Ambulance/transport services - Information services - Respite care.
- Equipment - Occupational therapy - Physiotherapy - Day care - Pharmacy
- Financial advice - Dietetics - Carer support services - Spiritual care - Community and voluntary sector support, including volunteers - Interpreter services

End of Life Care Strategy (2008)

**Key messages for commissioners**

- Comprehensive cross sector heart failure services have been shown to meet many of the supportive care needs.
- Effective utilisation of health, social care and the required range of supportive care services will require multi-agency strategic commissioning.
Care in the last days

Specific issues in heart failure
- Transition to the last days of life in heart failure is often hard to discern.
- Timely access to specialist palliative care services is sometimes difficult.
- All people with ICDs need consideration for deactivation of the defibrillator function.\(^\text{12}\).
- People often die because of multi-organ failure. This may trigger inappropriate investigation and intervention.
- The unpredictability of the course of the terminal phase may restrict choice of where patients are cared for and die.

Key messages for commissioners
- A multidisciplinary approach to care in the terminal phase with specialist palliative care involvement may improve care of the dying heart failure patient.
- The Liverpool Care Pathway has a specific heart failure section and provides a structured care plan for the dying phase. This also prompts the use of services to assess and address the ongoing needs of the carers after death.

‘Most, but not all people would prefer not to die in hospital – although this is in fact where most people do die’

End of Life Care Strategy (2008)
Care after death

Specific issues in heart failure
- Death may occur at a time of crisis, even when being transported to hospital or in the A & E department. This may disrupt the tenor of the passing and distress relatives. There may be difficulties in providing families with privacy and an appropriate area of relative tranquillity to take their leave.
- Sudden death in heart failure may complicate death certification or require the involvement of the coroner.
- The relatives of those who die suddenly are at a higher risk of complicated bereavement.
- Handling of implanted devices is important after death requiring deactivation of defibrillator function if applicable, and devices should be explanted prior to cremation. Interrogation of device data may sometimes be required by the coroner to aid clarification of the mechanism of death.

Key messages for commissioners
- Bereavement support should be integral to heart failure management.
- Provision and prompt access to chaplaincy services may be important for some families.
Appendix A

End of life care in heart failure

The diagram above illustrates a common disease trajectory in advanced heart failure. This representation shows how different phases can be identified and how the structure, aims and language of end of life care can be applied in heart failure.
Appendix B

Features of a commissioning framework to address the end of life needs of those with advanced heart failure

Local needs assessment
- Assess local heart failure disease burden
- Estimate volume of potential service requirement: local demographics and deprivation index
- Patient / carer views
- Baseline service review
- Prioritise areas for service development

Service provision
- Procure core elements of care required to meet anticipated domains of need for those with advanced heart failure
- Secure service volume commensurate with local need
- Construct multidisciplinary partnership to promote comprehensive support across all care sectors
- Define required competencies for accreditation of service providers
- Define roles and responsibilities of service partners to promote organisational cohesion
- Integrate end of life care with generic heart failure service

Clinical review process
- Use clinical opinion / agreed disease markers to trigger review
- Review by designated key heart failure professional with formal training in advanced communication
- Multidisciplinary assessment of needs and preferences of heart failure patients and carers
- Ensure user involvement
- Effective information gathering, archiving, and dissemination

Coordination
- Single point of contact for patient / carer
- Timely access to advice (24/7)
- Documentation of preferred place of care or death
- Advance care planning
- Define clinical parameters / mechanism for planned and unplanned reassessment anticipating clinical decline
- Links to out of hours / ambulance service
- Liaison between health, social services and charitable sector / voluntary services
- Effective information gathering and dissemination

Performance management
- Activity and capacity
- Partnership working
- Place of care / death
- Admission avoidance / reduced length of stay
- PROMS
- Clinical audit
- Reduced admissions

Fiscal process
- Costing of service elements
- Tracking of service efficiencies
- Incorporate end of life care within general tariff / HRG for heart failure

Data management
- Review information flows
Appendix C

Common disease trajectories in heart failure

Patients each have a unique disease trajectory. The diagrams above are common trajectories. The diagrams illustrate the need for supportive care services from diagnosis and the requirement to consider discussions about future care during stage 3 (period of instability).

Modified from Goodlin SJ, Copyright JACC (2009), with permission from Elsevier.
References


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NHS Improvement

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www.improvement.nhs.uk

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www.endoflifecareforadults.nhs.uk