Heart Failure Pathway



Cardiac Board

Improving quality, value and outcomes for people living with heart failure

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A pathway for clinicians and commissioners

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Contents

| Introduction | 3 |
|---|----|
| The pathway | 5 |
| Key messages | б |
| Stage 1 Prevention of heart failure | 8 |
| Stage 2 Case-finding and early diagnosis | 10 |
| Stage 3 Management of chronic heart failure | 14 |
| Stage 4 Management of decompensated and acute heart failure | 20 |
| Stage 5 Advanced therapies | 24 |
| Stage 6 End-of life and care for the dying person | 26 |
| Appendix 1 Understanding the phases of illness in heart failure | 33 |
| Glossary | 36 |

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Introduction

This is version one of a best-practice clinical pathway which has been prepared to support providers, public health commissioners and NHS commissioners to develop services and improve clinical outcomes for people with, or at risk of, heart failure. It will be subject to periodical updates and agreed changes that have been approved within local pathways and National Guidelines.

This pathway is a basic framework for health care professionals to work from and is inclusive of all the current National Guidance to support the care of patients with suspected of or having a diagnosis of Heart failure.

It should also be noted that the pathway was initially written prepandemic and data sources such as the BHF 'Blueprint for change', the Pumping Marvellous patient survey and NICE impact report on CVD management all suggest that the management and diagnosis of heart failure has been impacted by COVID 19. However, the full impact of this is currently unknown with providers adopting innovative offers of digital support, including home-based monitoring, home-based and digital provision of cardiac rehabilitation and virtual consultations.

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It is acknowledged that inequities exist in the access to resources and service provision across the locality and therefore it is expected that adoption and implementation of the pathway will be determined at each place within its own priority time-frame. This will be supported by local implementation plans within the Integrated Care system and Primacy care Networks and would also include provision of targeted education. It is hoped that it will prove to be a practical guide that will help to encourage discussion and collaboration between different stakeholders and help to deliver clinically effective and coordinated holistic services for people with heart failure, or at risk of heart failure, across the full pathway of care.

This pathway focuses on the standard of care that one would expect to receive if suspected of heart failure or following a diagnosis of heart failure. It does not, however, comprehensively cover every single clinical anomaly that may arise in clinical practice.

Key message for commissioners

The NHS and Public Health Outcome Frameworks together with the **Clinical Commissioning Outcome** Indicator Set place an ambition for a reduction in mortality in people under 75 years of age from cardiovascular disease. The inclusion of the under-75 mortality rate from cardiovascular disease means that all commissioners across the pathway will have a major role to play in ensuring that services focus on identifying people with suspected heart failure, in both acute and community settings, and treating those with a diagnosis of heart failure effectively to improve quality of life and prevent deterioration of the disease.

Across England, it is estimated that around a quarter of people with heart failure are undetected and untreated and current estimates suggest that in Cheshire and Merseyside (C&M) that equates to approximately 6,442 undetected heart failure cases. In Cheshire and Merseyside (C&M) there are 32,079 people who have a primary care diagnosis of heart failure equating to 1.2% of the overall population with reported prevalence from 0.97% (NHS Warrington CCG) to 1.6% (NHS South Sefton CCG). Statistically, Cheshire and Merseyside's heart failure prevalence is significantly higher than the National average rate (0.9%).

In the period October 2018 to September 2019, there were approximately 3,400 non-elective heart failure admissions reported, equating to £11.9m (based on average tariff £3,512). There were approximately 1,400 elective admissions during the same time period equating to £1.3m (based on average tariff £939). The volume and average cost of elective care heart failure admissions varies significantly across C&M CCGs.

Across C&M the average length of stay (LoS) following a non-elective admission for heart failure stands at 9.4 days which is slightly higher than the England average rate of 9.2 days. Across Cheshire and Merseyside CCGs, LoS varies from 11.6 days to 8.2 days. The average LoS following an elective admission is 10.7 days (varies 4 days to 13 days across CCGs). In total, 749 (22.4%) patients were readmitted to hospital within 30 days following a non-elective heart failure admission equating to £2.6m (based on average tariff £3,512).

Commissioning effective services for people living with heart failure, such as cardiac rehabilitation for example, can deliver a 25% relative risk reduction in unplanned admissions (see page 18). As mentioned above, this pathway should be used as a vehicle for collaboration between commissioners and providers to improve outcomes for people living with heart failure.



Aims of the pathway

The short and long-term aims of implementing a pathway for heart failure across different care settings are based on five fundamental principles:

- 1 Prevention of heart failure
- 2 Case-finding and early diagnosis
- **3** Management and treatment of heart failure in acute and long-term settings
- 4 Early identification and management of worsening symptoms
- **5** Support required during the phases of illness and at the end of life

Who is this document for?

- Providers of heart failure related services
- Primary and community care
- Patients
- Consultants in public health
- Public health commissioners
- Clinical Commissioning Groups
- NHS England



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The pathway

The diagram below sets out the six essential stages of patient management across the pathway of heart failure related care. The detail at each stage of the pathway incorporates five elements; a flow chart on how to manage someone with heart failure or suspected heart failure, a set of indicators (process and outcome measures – *Note:* the indicators are suggestions only and can used or developed further with commissioners and providers), guidelines, standards and, if appropriate, recognised competencies. This format provides validity in the measurement, efficiency and clinical effectiveness across the pathway thus providing confidence in the commissioning and provision of care.

Prevention

Case finding and early diagnosis

Management of chronic heart failure

Management of decompensated and acute heart failure

Advanced therapies

End-of-life and care for the dying person

Five phases of illness/ end-of-life care ۲



Key messages arising from this pathway

| 1 Prevention of heart failure | Heart failure is not inevitable and there are a number of opportunities to reduce the severity and even prevent the onset of heart failure. It is important that patients are given timely lifestyle advice on regular physical activity, maintaining a healthy weight and diet and avoiding smoking, alcohol or drug abuse. For those with predisposing health conditions such as a previous heart attack, high blood pressure or diabetes (this is not a comprehensive list) optimising medical treatments and lifestyle interventions alongside advising that patients continue to take prescribed medication regularly will protect heart muscle function. For anyone identified with heart failure, secondary prevention in the form of cardiac rehabilitation is extremely important and all patients should be referred. |
|--|--|
| 2 NT-proBNP / BNP | BNP is B type Natriuretic Peptide. It has a high negative predictive value in the diagnosis of heart failure. It is released in response to ventricular stretch. It is raised by heart failure, as well as left ventricular hypertrophy, atrial fibrillation, sepsis, chronic hypoxia, respiratory causes such as PE and pulmonary hypertension, and renal failure, liver cirrhosis and digoxin. It can be reduced by ACE inhibitors, ARBs, MRAs, diuretics and treating obesity. Therefore, in those patients with chronic stable heart failure on the correct medication, the BNP result may not be raised. Therefore, whilst BNP can help in suspecting heart failure, the gold standard for diagnosis is an echocardiogram. |
| 3 The breathless patient | The possibility of a heart failure syndrome should always be considered in the early assessment of the breathless patient. The simple and accessible blood test, NT-ProBNP (or BNP), provides high sensitivity for a diagnosis of heart failure and should be a first-line investigation in any breathlessness diagnostic pathway. This approach will enable rapid recognition of patients with heart failure, allowing timely access to specialist care and heart failure treatments, which improve heart failure symptoms whilst significantly reducing morbidity and mortality. |
| 4 Who to call for advice | In-patients should be reviewed by hospital Heart Failure Specialist Nurse (HFSN) prior to discharge for education and given community HFSN team contact details. Patients to contact community team if any HF concerns even prior to initial appointment. All HF teams should have dedicated answer machine facility for patients to contact and leave messages, staffed Mon–Fri office hours/response within 24 hours (note: fax not appropriate) Best practice Patients should have the ability to contact named HF nurse/team from other platforms – email (patient access email), access to HF team mobile giving ability for SMS updates Professionals – AHP email access, access to mobile phone. Teams to hold an SOS list for patients discharged to GP to enable patients direct access if condition should change within a 6 month window. When to call for advice Any change in heart failure symptoms e.g. oedema, orthopnoea, weight gain, dizziness & palpitations Symptoms as a result of medication changes 999 if syncope, acute SOB at rest, sustained symptomatic tachycardia/bradycardia GP Non-heart failure related symptoms Simple titration of heart failure medication as recommended by HF team Once fully discharged from heart failure follow up, routine six-monthly medication and blood result review |
| 5 Considering comorbidities (especially in palliative care) | Heart failure symptoms or clinical signs are often non-specific and exclusion of other causes or exacerbations of existing medical conditions is recommended. Symptoms and signs may present differently and may be more difficult to identify or interpret in e.g. obese patients, elderly or young. When considering a move towards a palliative care focus, pre-existing conditions should be taken into account and a multidisciplinary approach should be applied. It is advised that the multidisciplinary team negotiate involvement depending on presenting symptoms; specialist palliative care services should be considered. |
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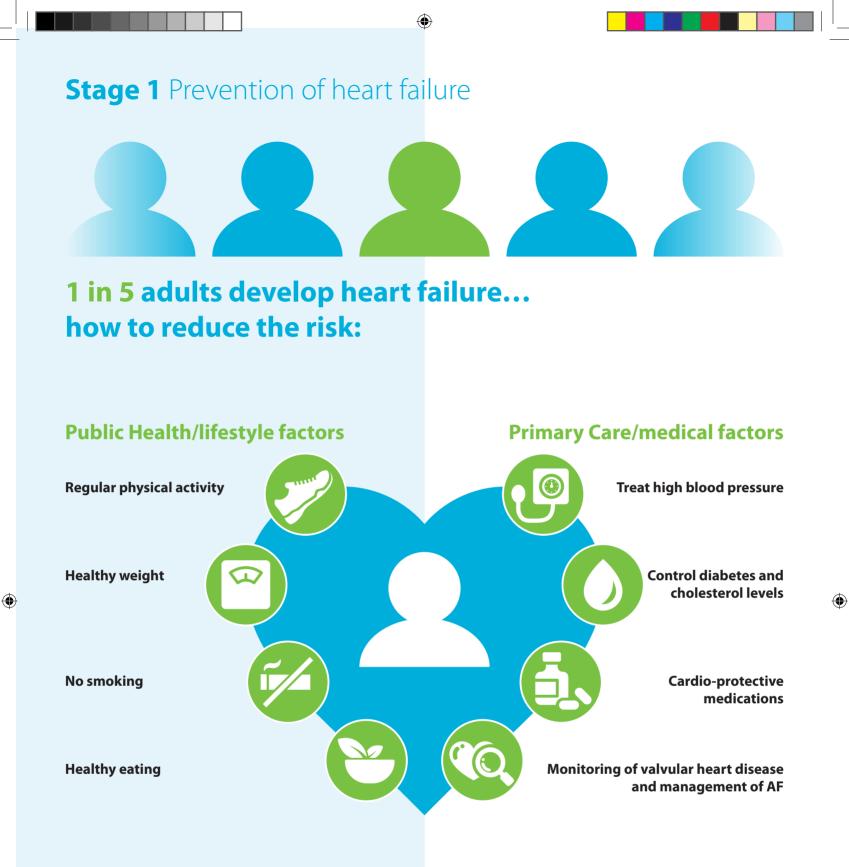
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| 6 Renal function | During initiation and titration of RAAS inhibitors, testing renal function is mandatory; a decline in renal function of UP TO 30% can be acceptable. During intercurrent illness, there is no evidence that stopping RAAS inhibitor is beneficial, but if patient is hypotensive, potassium rises above 6.0 mmol/L, or creatinine rises more than 30%, RAAS inhibitors should be reduced in dose or temporarily withheld. The HF specialist team should be consulted or informed of this decision as soon as practicable. The Renal Association & Resuscitation Council recommendation for reassessment of patients with hyperkalaemia is for serum potassium levels > 5.5 and treatment being required if they have hyperkalaemia associated ECG changes or if levels are > 6.0. https://renal.org/sites/renal.org/files/ RENAL ASSOCIATION HYPERKALAEMIA GUIDELINE 2020.pdf – algorithms on pages 156–158 provide a summary. In patients with fluid retention, high doses of diuretic are needed and a decline in renal function is not an indication to reduce diuretic dose: if the patient remains congested, more diuretics are required. If the patient is hypovolaemic or hypotensive, diuretics should be stopped or withheld temporarily. The only way to tell if a patient has fluid retention, is just right, or is hypovolaemic is to examine them clinically. Towards end-of-life, consider stopping RAAS inhibitors. RAAS inhibition has no known prognostic benefit in heart failure with preserved ejection fraction. Efforts should be made to initiate, titrate and maintain patients with HFrEF on RAAS inhibitor treatment, whether during intercurrent illness or worsening heart failure. Clark AL, Kalra PR, Petrie MC, et al Change in renal function associated with drug treatment in heart failure: national guidance. Heart 2019;105:904-910 |
|---|--|
| 7 Cardiac rehabilitation | All patients with heart failure symptoms and a confirmed diagnosis of either HFrEF or HFpEF should be offered cardiac rehabilitation (CR). For patients with HFrEF, attending and completing a course of exercise-based CR has been shown to dramatically reduce unplanned hospital admissions (any cause and HF-related) and improve quality of life. For patients with HFpEF, CR results in improved exercise capacity and quality of life. CR should commence as soon as possible once the diagnosis has been confirmed and if/when acute hospital care is not required. |
| 8 Phase of illness | 'Phase of Illness' is a term used in advanced illness to describe the distinct stages of an individual's illness. Patients are classified into one of five phases defined as either 'stable', 'unstable', 'deteriorating', 'dying', or 'deceased'. Phases are classified according to the care needs of the patient and their family and give an indication of the care needs of the individual, the family and suitability of the current care plan to address these needs. Phase of Illness is (except for the dying and deceased phases) not reliant on stage of disease and prognosis, and patients may move between phases in any sequence. Acutely Decompensated Heart Failure is the rapid worsening of symptoms and/or signs of HF—as a |
| Defining decompensated heart failure | de novo presentation or in a known HF patient—that warrant immediate medical intervention. |
| 10 Clinical judgement for echo- cardiography and sacubitril/ valsartan | All patients referred for sacubitril/ valsartan will need an echocardiogram with EF documented. Plus consideration of coronary angiogram/cardiac MRI/CT angiogram based on practitioners discretion. Echo to be within one year of referral for sacubitril valsartan unless: • Clearly documented ischaemic cardiomyopathy • Underlying non-reversible cause Repeat echo may be indicated for some patients with decompensated episodes and/or worsening symptoms to rule out other structural change not previously noted e.g. valvular function Echo not indicated to recheck LV function once stabilised on sacubitril valsartan Sacubitril valsartan not to be stopped if LV function improved above severe LVSD EF >35 |



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Adapted from Horwich, T. Fonarow, G. (2017). Prevention of Heart Failure. JAMA cardiology patient page. doi:10.1001/jamacardio.2016.3394



Core components of prevention

| Components | Measures and guidance |
|------------|--|
| Guidelines | Public Health England Local Health and Care Planning: Menu of preventative interventions (Nov 2016) Cheshire and Merseyside Strategic Clinical Network. Clinical pathway for people with atrial fibrillation or at risk of atrial fibrillation. Health and Care Partnership for Cheshire and Merseyside. Clinical and commissioning pathway for the prevention and management of dyslipidaemia and hypercholesterolaemia. Hypertension in adults: diagnosis and management NICE guideline [NG136] (2019) Chronic kidney disease in adults: assessment and management Clinical guideline [CG182] (2015) NICE AF guidance: https://www.nice.org.uk/guidance/ng196 |

Stage one

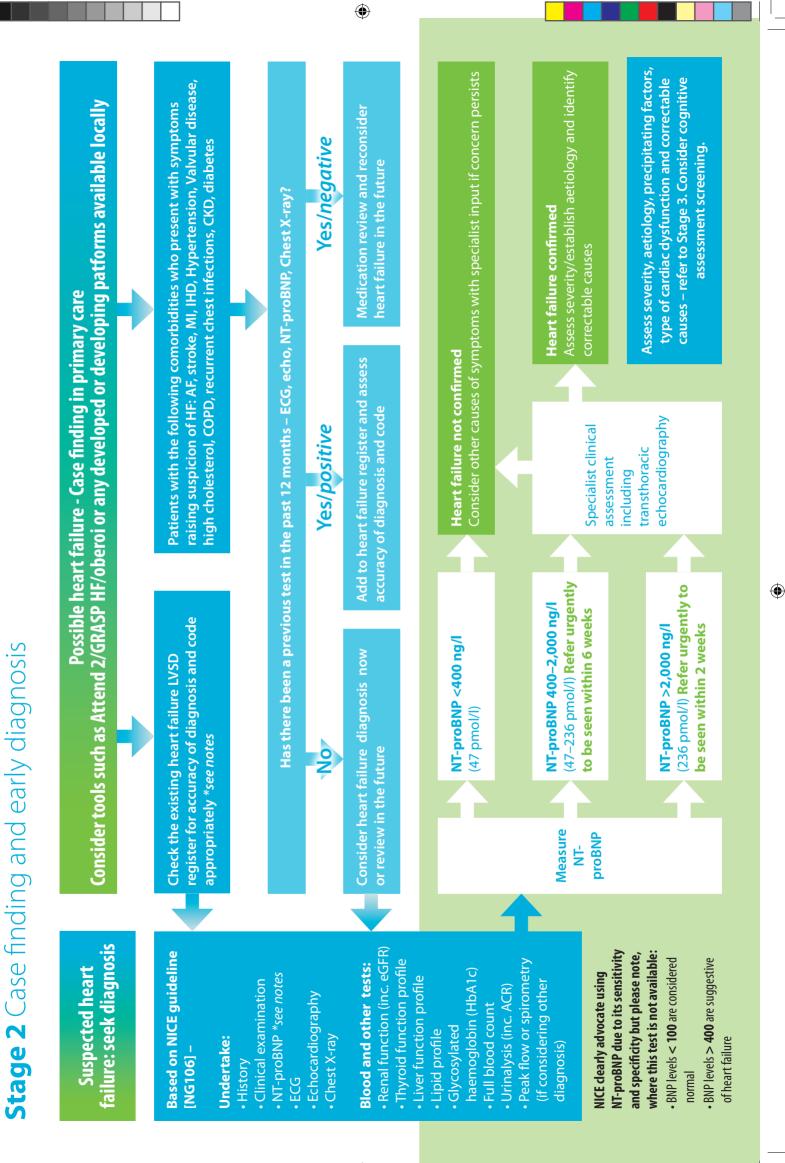
Heart failure is not inevitable and there are a number of opportunities to reduce the severity and even prevent the onset of heart failure. It is important that patients are given timely lifestyle advice on regular physical activity, maintaining a healthy weight and diet and avoiding smoking, alcohol or drug abuse. For those with pre-disposing health conditions such as a previous heart attack, high blood pressure or diabetes (this is not a comprehensive list) optimising medical treatments and lifestyle interventions alongside advising that patients continue to take prescribed medication regularly will protect heart muscle function.

For anyone identified with heart failure, secondary prevention in the form of cardiac rehabilitation is extremely important and all patients should be referred.

Web links

- Cheshire and Merseyside Strategic Clinical Network. Clinical pathway for people with atrial fibrillation or at risk of atrial fibrillation: https://www.nwcscnsenate.nhs.uk/files/1414/4543/7970/AF_Pathway_Master_FINAL_OCTOBER_2015. pdf?PDFPATHWAY=PDF
- Hypertension in adults: diagnosis and management NICE guideline [NG136] (2019): https://www.nice.org.uk/guidance/ng136





| Components | Measures and guidance |
|------------|---|
| Indicators | Number of patients on the heart failure register Proportion of people who have had NT-proBNP blood test Proportion of patients seen within 2 weeks if NT-proBNP>2000 Proportion of patients seen within 6 weeks if NT-proBNP 400–2000 Proportion of people who have had echocardiography after positive NT-proBNP Diagnosis of heart failure but not coded |
| Guidelines | NICE guideline [NG106]. Chronic heart failure in adults: diagnosis and management European Society of Cardiology (2016). Acute and Chronic Heart Failure Clinical Practice Guidelines [report] National Confidential Enquiry into Patient Outcome and Death – Acute Heart Failure (2018) https://www.ncepod.org.uk/2018ahf.html |

Core components of case finding in primary care

Stage two

Across England, it is estimated that around a quarter of people with heart failure are undetected and untreated and current estimates suggest that in Cheshire and Merseyside (C&M) that equates to approximately 6,442 undetected heart failure cases. There are 32,079 people who have a primary care diagnosis of heart failure equating to 1.2% of the overall C&M population with with reported prevalence from 0.97% (NHS Warrington CCG) to 1.6% (NHS South Sefton CCG). Statistically, Cheshire and Merseyside's heart failure prevalence is significantly higher than the National average rate (0.9%).

Diagnostics

BNP/NT-proBNP and factors which influence it

BNP/NT-proBNP is released in response to ventricular stretch and is raised by heart failure, as well as left ventricular hypertrophy, atrial fibrillation, sepsis, chronic hypoxia, respiratory causes such as PE and pulmonary hypertension, and renal failure, liver cirrhosis and digoxin. It can be reduced by ACE inhibitors, ARBs, MRAs, diuretics and obesity.

Echocardiography

NICE (NG106) recommend transthoracic echocardiography to exclude important valve disease, assess the systolic (and diastolic) function of the (left) ventricle, and detect intracardiac shunts. Transthoracic echocardiography should be performed on high-resolution equipment by experienced operators trained to the relevant professional standards. Need and demand for these studies should not compromise quality and those that report echocardiography are experienced in doing so. Current typical echocardiogram reports will classify the left ventricular systolic function as a category classification (i.e.) within normal limits, mild dysfunction, moderate dysfunction, severe dysfunction or critically severe dysfunction. These categories do not specifically correlate to ejection fraction percentage and cannot therefore be used to represent a specific band width of percentages, as there is a crossover between the boundaries of classification.

To ensure the echocardiogram report fully informs diagnosis and supporting the ongoing treatment plan of a patient with suspected (or living with) heart failure, it is vital that, on the referral form, the referring clinician or practitioner requests the left ventricular ejection fraction calculation within the *'reason for referral'* box. This will ensure and advise the cardiac physiologist or physician performing the scan that a left ventricular ejection fraction is needed to support diagnosis or ongoing care and helps to define the type of heart failure.

Heart failure can be defined on the basis of left ventricular ejection fraction (LVEF) as heart failure with reduced ejection fraction (HF-rEF) or heart failure with preserved ejection fraction (HF-pEF).

Heart failure with reduced ejection fraction (also referred to as HF with systolic dysfunction) is defined as the presence of signs and symptoms of HF with a left ventricular ejection fraction of <40% (although the cut-off level varies from \leq 35% to \leq 40% or \leq 45%).

Heart failure with preserved ejection fraction is defined as the presence of signs and symptoms of HF with a normal or only mildly reduced ejection fraction, with an undilated left ventricle. There should be evidence of other relevant structural heart disease (left atrial enlargement, left ventricular hypertrophy) or raised natriuretic peptides or evidence of left ventricular diastolic dysfunction. This has been previously known as diastolic dysfunction heart failure or diastolic heart failure.



Identification of new and existing patients in Primary Care

Heart failure admissions in the UK are high and usually prolonged with consequent burden on the NHS workforce and resources, as well as significant morbidity and mortality for heart failure patients. Early identification of patients who have not yet been diagnosed with heart failure, would provide opportunity for early therapeutic interventions thus reducing unplanned hospital admissions, improving prognosis, morbidity and mortality.

Furthermore, many patients who have already been treated for heart failure, at least partially, fail to be captured on NHS IT systems or to be seen by a heart failure specialist; these patients remain at high risk of morbidity and mortality without the correct therapies.

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Identification of new and existing patients in primary care requires:

1 Detection of asymptomatic patients who are at high risk of developing heart failure symptoms, including:

- Patients who have had a previous myocardial infarction.
- Patients with high risk comorbidities i.e.
 - coronary artery disease
 - atrial fibrillation
 - valvular heart disease
 - diabetes mellitus
 - hypertension
 - hyperlipidaemia
- Patients with lifestyle risk factors i.e.
 - smoking
 - obesity

Primary care disease registers & IT systems and commercial tools can be utilised to case-find these high-risk patients. Examples include GRASP-HF, Attend2 or Oberoi HF (see references in the Glossary on page 36). You may also want to consider any tools that may be in development locally.

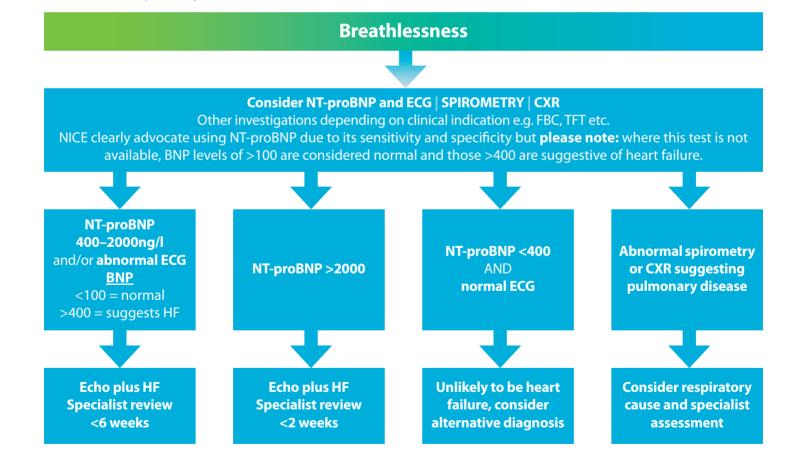


2 Rapid diagnosis of *symptomatic* patients who may have heart failure requires awareness of the symptoms and signs of HF, as well as swift access to diagnostic tests and specialist assessment. However, the symptoms and signs of heart failure can be vague and apply to other conditions such as respiratory disease; whilst patients and clinicians often attribute fatigue and breathlessness to ageing and lack of fitness.

Increased public and clinician education of the potential causes of such symptoms, combined with clearly defined and accessible pathways for assessment could aid earlier diagnosis. The benefits of a *breathlessness pathway* would be to ensure heart failure is always considered in the dyspnoeic patient, otherwise we risk delaying rapid access to treatments to improve prognosis with consequent escalation of heart failure morbidity and mortality. The breathlessness pathway illustrated below suggests early use of NT-proBNP combined with ECG, spirometry, chest X-ray and blood tests as these are generally easily accessible to primary care across the UK. This combination of investigations would rapidly facilitate the next steps of appropriate specialist investigation and assessment to allow the patient to see the right specialist first time. This pathway could be adapted, depending on local expertise, to be delivered by primary or integrated community services to facilitate non-specialist confidence in the early diagnosis of heart failure.

Breathlessness pathway

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| Specialist advice/intervention | If already on ACE, replace with Sacubitril-Valsartan (ARNI) as per NICE TA https://www.nice.org.uk/guidance/ta388 | <pre>lvabradine if in SR and HR>75 bpm in severe LVSD or EF <35% https://www.nice.org.uk/guidance/ta267</pre> | If symptoms persist seek specialist advice to | consider the following treatments Digoxin for worsening HF https://www.nice.org.uk/guidance/cg180/ | CRT-P or CRT-D or ICD as per NICE TAG314 | Advanced heart failure therapies (see stage 5) | <u>نت</u> | hydralazine guidance/pathways. ESC Guidelines for the diagnosis and treatment of acute and chronic heart <i>Lul 1/2016</i>) <i>Jul</i> | | ICD/CRT discussion if applicable ICD/CRT discussion if applicable All patients should be offered the opportunity of an Advanced Care Planning discussion. Agree on-going monitoring and support to avert crisis Agree on-going monitoring and support to avert crisis Cachexia Worsening U&Es/LFTs Frailty No reversible cause Low blood pressure Maximum tolerated therapy Two or more hospital admissions within last six months Comorbidities |
|--|--|---|---|--|---|---|---|---|--|---|
| Speci | | | lf sy pers spe | cons fol trea | | | If AR int | byd pre | | ICD/CRT discu All patients sl Advanced Car Agree on-goi |
| c of chronic heart failure gorithm for ew of therapies | Heart failure diagnosed by a specialist | Offer diuretics to relieve congestion symptoms | Heart failure syndrome AND significant** LVSD Evidence of moderate or severe LVSD on imaging | EF <40% on imaging NT-proBNP>400 (BNP>100) ** significant LVSD implies a visual description of LV | systolic function to be moderately impaired or worse, and/or a calculated EF of < 40% | Commence ARNI (if LVEF<35%) /ACE/ARB +BB +MRA +Dapagliflozin https://www.nice.org.uk/guidance/ta679 CaReMeuk algorithm | https://www.bsh.org.uk Optimise therapy and monitor adherence https://www.panmerseyapc.nhs.uk | Cardiac rehabilitation for all HF patients unless unstable | egree of LV systolic dysfunction should be considered for strongest in those patients with a defined EF of < 40% | reviewed regularly • Request consent to share information and create EPaCCS record • A holistic needs assessment and a keyworker identified (including benefits (blue badge, prescription exemption etc.) and individual needs identified that are important are explored, respected and met as far as possible) |
| Stage 3 Management of chronic heart failu Chronic heart failure treatment algorithm for new diagnoses and long-term review of therapies | Heart failure diagn | Offer diuretics to reliev | Heart failure syndrome but NOT significant LVSD | NT-proBNP>400 (BNP>100) Mild LVSD - EF >40% on imaging* • Left atrial enlargement | Left ventricular hypertrophy Echo parameters for diastolic dysfunction | | Optimise treatment of co-morbidities and lifestyle | Cardiac rehabilitation for all | * Note – patients with heart failure symptoms and any degree of LV systolic dysfunction should be considered for ACEi and BB but the evidence base for efficacy remains strongest in those patients with a defined EF of $<$ 40% | Phase of illness – have you considered? Patient identified as deteriorating despite effective management of underlying medical condition(s) Clear, sensitive communication with patient and those identified as important to them Including patient on the Supportive Care Record / GP Gold Standards Framework register and their care |

Chronic heart failure long-term management: achieving multidisciplinary team working

The heart failure multidisciplinary team

Multi-morbidity is frequent in patients with chronic heart failure and multidisciplinary working cross sector is essential to deliver high-quality care for these patients; that is coordinated and continuous healthcare delivery with an understanding of the workforce roles and responsibilities, supported by clear channels of communication, which then facilitate opportunities for shared learning and education. This will enable heart failure patients to have timely access to healthcare and seeing the right clinician, in the right place, first time.

The heart failure multidisciplinary team (patient/their carers, HF specialist nurse, HF cardiologist, pharmacist, renal elderly care, primary care, chest, cardiac rehabilitation, psychologist, palliative care team) with headline responsibilities listed:

Heart Failure Specialist offered in both hospital and community locations. The core specialist heart failure multidisciplinary team includes:

- A lead physician with subspecialty training in heart failure (usually a Consultant Cardiologist) who is responsible for making the clinical diagnosis
- A Specialist Heart Failure Nurse

• A healthcare professional with expertise in specialist prescribing for heart failure (Adapted from NICE's Guideline on chronic heart failure in Adults rec 1.1.1)

- Diagnosis of heart failure syndrome and stage, including end of life
- Acute Care
- Development of long-term management plan including patient and carer/family education.
- Reassessment of decompensating heart failure

- Specialist only interventions i.e. sacrubitil valsartan, cardiac devices
- Advising on complex problems with difficult decision making
- Routine monitoring of patients with severe heart failure syndromes
- Consider the use of technology for remote monitoring of heart failure relapse

Primary care (GP, Practice nurse, HCA, physician assistant, pharmacist) Carly symptom recognition and investigation and

- investigation, referral for diagnosis, and identification of end of life stage
- Ensuring co-ordinated care
- 6–12-month review for all heart failure patients including optimisation of comorbidities
- Lifestyle counselling and interventions
- Escalation of complex or worsening heart failure

Community services (DN, CCP)

Care of housebound patients

- Support with IV diuretics at home/ ambulatory clinic
- Palliative care

Cardiac Rehabilitation

A comprehensive programme accessible for all patients that provides advice and support on lifestyle and risk management, pyschosocial health, education health and behaviour change and physical activity. This is offered in a variety of locations. https://www.bacpr.com/resources/ BACPR_Standards_and_Core_ Components_2017.pdf

Cardiac diagnostics

- ECG and echo
- CMR and other imaging
- Expert support in interpretation

Palliative Care services

Specialist care for all end of life heart failure patients including housebound who have complex issues that cannot be managed by their Nursing Team

Other specialists to manage complex comorbidities e.g. nephrology and respiratory

To link to MDT for support with difficult decision making in the context of multimorbidity



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Social Care

Social care provision in increasing frailty

Chronic heart failure: 6–12 month condition and therapy review

Patients with chronic heart failure will see a variety of clinicians depending on their severity and co-morbidities. It is the responsibility of all who treat chronic heart failure patients to ensure regular review of their therapy and management plan. The frequency of this review will depend on the stability of symptoms but should be 6–12 monthly as a minimum. The reviewing clinician should ensure the following;

- Reassessment of the stage of heart failure as per flowchart page 14. This will include evaluation of the New York Heart Association (NYHA) score (see page 17) and assess need for repeat imaging to re-evaluate LV function (consider annual echo) and ensure treatment is appropriate for the patient's heart failure syndrome e.g. reassessment for cardiac device;
- Medical therapy should remain optimised as per flowchart page 14 – this should include safety checks including assessment of side effects, drug interactions (contraception for women of child bearing age), blood pressure, pulse and blood test monitoring;
- Cardiac rehabilitation has been offered;
- Co-morbidities are optimised;
- Lifestyle modifications have been optimised;
- Consider the need for cognitive assessment;
- Consider the impact of heart failure on their employment status;
- Consider social care assessment, including assessment of social isolation;
- Identification of end stage heart failure and consideration of need for palliative care and advance planning as per page 26.

Core components of chronic heart failure management

| Components | Measures and guidance |
|------------|--|
| Indicators | Number of patients with an accurate diagnosis of heart failure Proportion of patients with HFrEF Proportion of patients with HFmREF Proportion of patients with HFpEF Proportion of patients referred to a heart failure service Proportion of patients referred to a heart failure service that are seen within 2 weeks Number of available clinic slots Number of available home visit slots Proportion of patients who have had a medication review and are on maximum tolerated dose / target dose Proportion of patients who are referred to smoking cessation, dietician, alcohol advice, counselling Proportion of patients offered cardiac rehabilitation Proportion of patients referred to cardiac rehabilitation Proportion of patients accepted cardiac rehabilitation Proportion of patients commenced cardiac rehabilitation Proportion of patients completed cardiac rehabilitation |
| Standards | ACPICR Standards for Physical Activity and Exercise in the Cardiovascular Population (2015) Chronic Heart failure Quality standards– Chronic heart failure in adults (QS9), Quality Statements 1–7 https://www.bacpr.com/resources/BACPR_Standards_and_Core_Components_2017.pdf |
| Guidelines | NICE guideline [NG106]. Chronic heart failure in adults: diagnosis and management European Society of Cardiology (2016). Acute and Chronic Heart Failure Clinical Practice Guidelines Pan-Mersey pharmacological guidance on heart failure medications British Society of Cardiovascular Prevention and Rehabilitation (2017) BNF/EMC/SPC |

Stage three

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Discharging a patient back to general practice

All patients with heart failure including patients with HFpEF should have access to community HF services. The community heart failure service will discharge a patient back to primary care for routine monitoring (at least every six months) when:

- **The patient is fully titrated on maximum tolerated heart failure medication.**
- **The patient is stable and/or when specialist input no longer required/appropriate**
- The patient has been considered for device therapy and/or sacubitril valsartan.
- The patient has been assessed for iron deficiency/iron deficiency anaemia and considered for i.v. ferric carboxymaltose, if appropriate.
- Offered cardiac rehabilitation with support for patient's self-management and adjustment of their diuretic therapies
- Primary Care Management would also be for people with HF-pEF patients do not usually require ongoing specialist review as management is of their comorbidities and diuretic therapy.
 - Once optimised discharge back to GP with 3-month open appointment
- Palliation



Cardiac diagnostics

Coronary angiography (CT or invasive) to ascertain need for revascularisation and aetiology, Holter monitoring.

Cardiac devices

Implantable cardioverter defibrillators (ICDs) are recommended as options for:

Treating people with previous serious ventricular arrhythmia, that is, people who, without a treatable cause:

- Have survived a cardiac arrest caused by either ventricular tachycardia (VT) or ventricular fibrillation or
- Have spontaneous sustained VT causing syncope or significant haemodynamic compromise or

 Have sustained VT without syncope or cardiac arrest, and also have an associated reduction in left ventricular ejection fraction (LVEF) of 35% or less but their symptoms are no worse than class III of the New York Heart Association (NYHA) functional classification of heart failure.

Treating people who:

- Have a familial cardiac condition with a high risk of sudden death, such as long QT syndrome, hypertrophic cardiomyopathy, Brugada syndrome or arrhythmogenic right ventricular dysplasia or
- Have undergone surgical repair of congenital heart disease.

Implantable cardioverter defibrillators (ICDs), cardiac resynchronisation therapy (CRT) with defibrillator (CRT D) or CRT with pacing (CRT P) are recommended as treatment options for people with heart failure who have left ventricular dysfunction with a left ventricular ejection fraction (LVEF) of 35% or less. For further information including a table of options please see https://www.nice. org.uk/guidance/ta314/chapter/1-Guidance

Comprehensive discharge summary should contain confirmation of the diagnosis being clear [if known] or plan to find out.

New York Heart Association (NYHA) Functional Classification

| Class | Patient Symptoms |
|-------|--|
| I. | No limitation of physical activity. Ordinary physical activity does not cause undue fatigue, palpitation, dyspnoea (shortness of breath). |
| H | Slight limitation of physical activity. Comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnoea (shortness of breath). |
| ш | Marked limitation of physical activity. Comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnoea. |
| IV | Unable to carry on any physical activity without discomfort. Symptoms of heart failure at rest. If any physical activity is undertaken, discomfort increases. |

Original source: Criteria Committee, New York Heart Association, Inc. Diseases of the Heart and Blood Vessels. Nomenclature and Criteria for diagnosis, 6th edition Boston, Little, Brown and Co. 1964, p 114.



Cardiac rehabilitation

The third edition (2017) of the British Associations of Cardiovascular Prevention and Rehabilitation (BACPR) Standards & Core Components represents current evidence-based practice and a pragmatic overview of the structure and function of Cardiovascular Prevention and Rehabilitation Programmes (CPRPs) in the UK.

Guidelines can be accessed here:

https://www.bacpr.com/resources/BACPR_Standards_ and_Core_Components_2017.pdf

Details of REACH-HF are located in the glossary (page 36).

The evidence base for CR in people living with heart failure is strong and embedded in all national and international heart failure guidelines. For individuals with a diagnosis of HFrEF, exercise-based programmes of CR impact favourably on all-cause acute hospitalisation, with a 25% relative risk reduction in unplanned admissions. The need for acute hospital care due specifically to heart failure related issues can be reduced by 39% (NNT 18) and overall quality of life significantly improved^{1, 2}. When the diagnosis is HFpEF, exercise-based CR again proves to be a very effective intervention, significantly out-performing standard heart failure drug therapies in terms of benefits on exercise capacity and quality of life measures³.

The referral criteria

New diagnosis of HF or recent step change in NYHA and

- Clinically stable for exercise
- CR staff need to know if the patient has been referred for device therapy and is the patient suitable and or been referred for sacubitril valsartan

Referral

Referral systems differ across Cheshire and Merseyside. Find out what your local provider referral system is. Initial assessment/inclusion for core heart failure cardiac rehabilitation should be as per BACPR Accreditation recommendation (currently within 33 days – England average).

Cardiac rehabilitation offer 8–12 week programme of education and exercise sessions hosted in a variety of venues – hospital, community and home-based. Patients are also offered virtual and digital offers of support to ensure their individual needs are met. Input from MDT should consist of CNS, exercise physiologist and or physiotherapist, dietician, pharmacist, occupational therapist, with psychological input and maintenance programme leaders.

Cardiac rehabilitation should be delivered in venues that are easily accessible with good transport links, with choice of day or time to ensure adherence to the programme. Recent evidence also supports the concept of home-based CR for patients with heart failure – a cost-effective option that may be particularly suited to older, multi-morbid heart failure patients who would otherwise have great difficulty in attending/completing conventional 'centre-based' programmes^{4, 5}.

MDT Management

As a minimum, the team should have a lead physician with heart failure expertise, a specialist heart failure nurse and a specialist heart failure prescriber. MDT roles may include:

- Securing the diagnosis and implementing/reviewing/ optimising therapies
- Providing education and sign-posting to other services such as rehabilitation and palliative care
- Assessing phase of illness and liaising with other healthcare professionals

Assessment of Cognitive Impairment (if necessary)

For an individual who is suspected as having a memory problem, or may have dementia, make an initial assessment by taking a history from the person and if possible from someone who knows them well (i.e. a family member). Use a validated brief structured cognitive testing instrument i.e. any one of the following:

- The 10-point cognitive screener (10-CS)
- The 6-item cognitive impairment test (6CIT)
- The 6-item screener
- The Memory Impairment Screen (MIS)
- The Mini-Cog
- Test Your Memory (TYM)

Ref: https://www.nice.org.uk/guidance/ng97/chapter/ Recommendations#diagnosis

References for this page

- 1 Sagar VA, Davies EJ, Briscoe S et al. Exercise-based rehabilitation for heart failure: systematic review and meta-analysis. Open Heart. 2015;2(1) Available at: http://openheart.bmj.com/ content/2/1/e000163
- 2 Long L, Mordi IR, Bridges C et al. Exercise-based cardiac rehabilitation for heart failure. Cochrane Database of Systematic Reviews. Cochrane Library. January 2019.
- 3 Morris JH, Leway C. Exercise training and Heart Failure: A review of the literature. Card Fail Rev. 2019 Feb: 5(1): 57-61
- 4 Dalal HM, Taylor RS, Jolly K et al. The effects and costs of homebased rehabilitation for heart failure with reduced ejection fraction: The REACH-HF multicentre randomized controlled trial. Eur J Prev Cardiol. 2019 Feb;26(3):262-272
- **5** Dalal HM, Lang CC, Smith K et al. A randomized controlled trial of a facilitated home-based rehabilitation intervention in patients with heart failure with preserved ejection fraction and their caregivers: REACH-HFpEF pilot study. Br J Gen Pract 2018; 68 (suppl 1): bjgp18X697013



Phase of illness relating to this stage

| Start of phase 1 Stable | End of phase | NW EOL model phases and Heart Failure stages |
|---|--|---|
| Patient problems and symptoms are adequately controlled by established plan of care. Further interventions to maintain symptom control and quality of life have been planned. Family/carer situation is relatively stable and no new issues are apparent | The needs of the patient and or family/ carer increase, requiring changes to the existing plan of care | Phase 1 Advancing disease Stage 3 Management of chronic heart failure |

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| Start of phase 2 Unstable | End of phase | NW EOL model phases and Heart Failure stages |
|---|---|---|
| An urgent change in the plan of care or emergency treatment is required because: Patient experiences a new problem that was not anticipated in the existing plan of care and/or Patient experiences a rapid increase in the severity of a current problem and/or Family/carers circumstances change suddenly impacting on patient care | The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/ or death is likely within days (i.e. patient is now terminal) | Phase 2 Increasing decline (amber) Stage 3 Management of chronic heart failure |



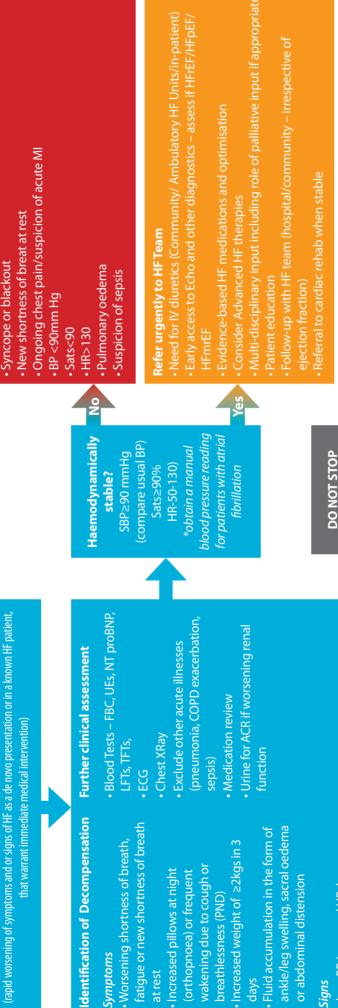
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Stage 4 Management of decompensated and acute heart failure

Acutely Decompensated Heart Failure

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<u>Refer to hospital or if in-patient (to HF Team) urgently if...</u>



 Low BP, increased HR, low oxygen previous observations if available) Peripheral oedema, Increased JVP, saturations (compare with Pulmonary Oedema sacral oedema

Work closely with other services e.g. Specialist Update EPaCCS Record as and when necessary

- Review or offer Advanced Care Plan, share Palliative Care
 - DNRCPR considered, outcome documented, information with patients consent
- information shared appropriately including ambulance service

Prioritised as appropriate Gold Standards Framework

Person and agreed others are involved in decisions

about treatment and care as they want

Clear, sensitive communication with patient and All reversible causes of deterioration explored

those identified as important to them

Phase of illness - have you considered?

Medical review

A holistic needs assessment and a keyworker

identified that are important are explored, respected prescription exemption etc.) and individual needs identified including benefits (e.g. blue badge, and met as far as possible.

Continuing Health Care funding

DS1500

An opportunity for an Advanced Care Planning ICD discussion and deactivation discussion?

alternate days or twice a week with close monitoring of renal function

Mineralocorticoid receptor antagonists (MRA): 12.5–25 mg daily

Consider adding in a Thiazide (Bendroflumethiazide 2.5 to 5 mg)

· If already on diuretics increase dose 1.5/2 times to maximum of

Furosemide 80 mg BD or eguivalent

If diuretic naive start Frusemide 40 mg OD/BD

DISCUSSING WITH

HF TEAM

WITHOUT

HF TREATMENTS

Primary Care Management

- Agree on-going monitoring and support to avert crisis
- **OOH/NWAS updated including DNACPR status and**
- **Advanced Care Plan**

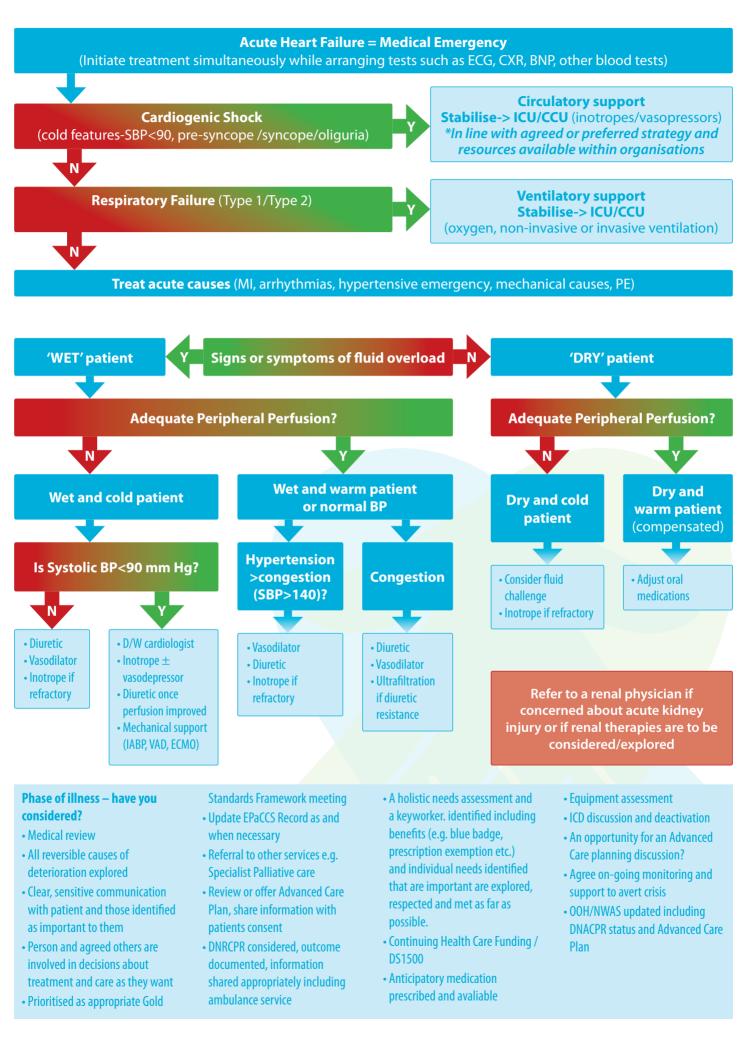
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meeting

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Note for use of Metolazone Therapy: consider as per local pathway and guidance

Management of acute heart failure



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Core components of decompensated and acute heart failure

| Components | Measures and guidance |
|--------------|--|
| Indicators | Number of patients identified as having decompensated heart failure Proportion of patients identified as having decompensated heart failure being admitted to hospital Proportion of heart failure admissions diagnosed as a new cases of heart failure Mean and median length of stay in patients admitted to hospital with decompensated heart failure Mean and median length of stay in patients admitted to hospital with acute heart failure Proportion of people admitted referred to heart failure specialists Number of patients with shared care plans Number of patients who have had a frailty assessment Number of patients who have had bloods for renal function Hospital mortality rate Number of failed discharges Patient experience / satisfaction measure Number of patients whose expectations are met regarding preferred place of care |
| Standards | Local 1. Acute HF patients seen by HF nurse 2. Acute HF patients seen by cardiologist 3. HFrEF patients started on BB, ACE, MRA 4. Follow up clinical assessment |
| Guidelines | Guide to diagnostics and therapeutics NICE guideline [NG106]. Chronic heart failure in adults: diagnosis and management European Society of Cardiology (2016). Acute and Chronic Heart Failure Clinical Practice Guidelines DNACPR Guide https://www.resus.org.uk/dnacpr/decisions-relating-to-cpr/ The Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) http://www.respectprocess.org.uk/dnacpr/do-not-attempt-cpr-model-forms/ |
| Competencies | Cardiology specialist training, subspecialty training in HF ESC HFA accreditation, exam https://www.nwcscnsenate.nhs.uk/files/7814/5070/6074/Cheshire_and_Merseyside_Heart_ failure_Nurse_Competency_Doc.pdf |



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Stage four

Issues

The North West Coast Strategic Clinical Network guide to the administration of parenteral diuretics in an out of hospital setting or as a day case can be accessed here:

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2019/06/administration-intravenous-subcutaneous-diuretics-heart-failure-patients.pdf

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- Definition of decompensated HF rapid worsening of symptoms and or signs of HF as a de novo presentation or in a known HF patient, that warrant immediate medical intervention
- Hypotension in the person with heart failure

Hypotension in a HF patient is defined as a systolic BP<90 and diastolic BP of <60 mm Hg. It is also important however to ascertain if there are symptoms accompanying hypotension (postural drop in BP, dizziness, syncope, frequent falls) as HF patients frequently tolerate hypotension on prognostic medications such as BB, RAASi. It is important to record the patient's stable BP in their care plan and encourage recording of BP by the patient at home and every healthcare visit, so the patient's 'normal BP' can be documented. Unless patient is symptomatic or new systolic BP <85, prognostic meds should not be withheld without consulting the HF specialist team.

Phase of illness

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| The care plan is addressing anticipated needs but requires periodic review because: Patient's overall functional status is declining and Patient experiences a gradual worsening of existing problem and/or Patient experiences a new but anticipated problem and/or Family/carers experience gradual worsening distress that impacts on the patient care Family/carers experience gradual worsen the patient care Death is likely within days (i.e. patient is now terminal) Patient condition plateaus (i.e. patient is now terminal) Phase 2–3 Increasing decline into dying phase Stage 4 Management of decompensated heart failure | Start of phase 2 Deteriorating | End of phase | NW EOL model phases and Heart Failure stages |
|---|---|--|---|
| • Frailty | needs but requires periodic review because: Patient's overall functional status is declining and Patient experiences a gradual worsening of existing problem and/or Patient experiences a new but anticipated problem and/or Family/carers experience gradual worsening distress that impacts on the patient care | is now stable) or An urgent change in the care plan or emergency treatment and/or Family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (ie patient is now unstable) or Death is likely within days (i.e. | Increasing decline into dying phase Stage 4 Management of decompensated heart |

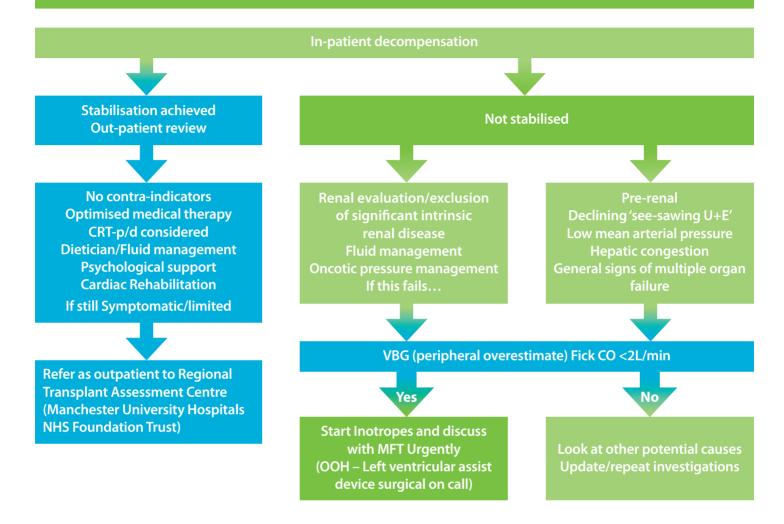


Stage 5 Advanced therapies

Contraindicators must be observed: *

If there is a concern or question that mechanical circulatory support or transplant would be needed, then a direct conversation with the transplant fellow on call during the day, or the LVAD surgical fellow at night, should be made. They are based at Manchester University NHS Foundation Trust (MFT).

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* http://www.jhltonline.org/pb/assets/raw/Health%20Advance/journals/healun/ISHLT_GUIDELINE.pdf

Advanced therapies

If there is any clinical uncertainty, discussion with the on-call transplant team at Manchester Foundation Trust should be considered, however, there are some absolute contraindications to Ventricular Assist Device / Transplantation as listed opposite:

- 1 Active significant substance abuse
- 2 Psychiatric illness that could jeopardise compliance (eg psychosis requiring treatment)
- 3 History of non-compliance
- 4 Diabetes with microvascular complications (eg proliferative retinopathy, diabetic nephropathy etc).
- 5 Solid organ or haematological malignancy.
- 6 Morbid Obesity. BMI >35. However, note that the local usual cut off is BMI 32 (only in exceptional circumstances would patients with BMI 32-35 be deemed appropriate).
- 7 Systemic (AL) Amyloidosis. ATTRwt (Wild Type Transthyretin Amyloidosis) is not a contraindication.



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Conventional criteria for heart transplantation

- Impaired LV systolic function
- NYHA III (eg, patient cannot climb one fight of stairs without symptoms) or IV symptoms
- Receiving optimal medical treatment (including target or maximum tolerated doses of b-adrenergic antagonists, ACE inhibitors and aldosterone antagonists)
- CRT, ICD or CRTD device implanted (if indicated)
- Evidence of a poor prognosis, for example:

i. Cardiorespiratory exercise testing (VO2 max <12 ml/kg/min if on b-blockade, <14 ml/kg/min if not on b-blockade, ensuring respiratory quotient ≥1.05)

ii. Markedly elevated BNP (or NT-proBNP) serum levels despite full medical treatment

iii. Established composite prognostic scoring system, such as the HFSS or SHFM

BNP, B-type natriuretic peptide; CRT, cardiac resynchronisation treatment; CRTD, CRT and ICD treatment; HFSS, Heart Failure Survival Score; ICD, implantable cardioverter defibrillator; LV, left ventricular; NT-proBNP, N-terminal pro-B-type natriuretic peptide; NYHA class IV, New York Heart Association; SHFM, Seattle Heart Failure Model.

Uncommon indications for transplantation

- Persistent haemodynamically compromising ventricular arrhythmias, refractory to all usual therapies (including antiarrhythmic drugs, catheter ablation, electrical device treatment, revascularisation)
- Refractory angina, where there is clear objective evidence of recurrent significant (debilitating) myocardial ischaemia that is not amenable to conventional treatment (including all forms of revascularisation and full anti-anginal treatment)
- Restrictive and hypertrophic cardiomyopathy with persisting NYHA III or IV symptoms refractory to conventional treatment and/or recurrent admissions with decompensated HF. Patients should have clear echocardiographic evidence of restrictive filling that can be confirmed by invasive haemodynamic studies, and the aetiology should be clearly identified to ascertain the presence of a systemic disease and the risk for recurrence following transplantation

HF, heart failure; NYHA class IV, New York Heart Association.

Clinical indicators that should prompt consideration for referral

Two or more admissions for treatment of decompensated HF within the last 12 months

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- Persistent clinical evidence of overt heart failure after optimised medical treatment
- Calculated SHFM score indicating a ≥20% 1-year mortality
- Echocardiographic evidence of right ventricular dysfunction or increasing pulmonary artery pressure on optimal treatment (aim to refer before the PA systolic pressure exceeds 50 mm Hg)
- Anaemia, involuntary weight loss, liver dysfunction or hyponatraemia attributable to heart failure
- Deteriorating renal function attributable to heart failure or inability to tolerate diuretic dosages sufficient to clear congestion without change in renal function (aim to refer before creatinine clearance falls below 50 ml/min or the eGFR falls below 40 ml/ min/1.73m²)
- Significant episodes of ventricular arrhythmia despite full drug and electrophysiology/device treatment
- Increasing plasma BNP or NT-proBNP levels despite adequate HF treatment

BNP, B-type natriuretic peptide; HF, heart failure; eGFR, estimated glomerular filtration rate; NT-proBNP, N-terminal pro-Btype natriuretic peptide; PA, pulmonary artery; SHFM, Seattle Heart Failure Model.

Indications for urgent inpatient referral

- Requirement of continuous inotrope infusion (or/ and intra-aortic balloon pump (IABP)) to prevent multiorgan failure
- No scope for revascularisation in the setting of ongoing coronary ischaemia
- Persisting circulatory shock due to a primary cardiac disorder
- An absence of contraindications to transplantation

Banner, N., Bonser, R., Clarke, A et al (2011). UK guidelines for referral and assessment of adults for heart transplantation. Heart 2011;97:1520e1527. doi:10.1136/heartjnl-2011-300048



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Stage 6 End-of-life and care for the dying person

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| / MAGGIC) • Cachexia | | | Comorbidities | Advanced frailty |
|--|---|--|--|---|
| • Worsening U&Es / LFTs | | | Resistant sympto | |
| • Two or more hospital admis | sions within the | | Maximum tolerat | |
| | | | | |
| | | | | - |
| Referral to: | | | Person-cent | tred care approach - shared |
| Specialist Palliative Care | | | | king around: |
| Hospice day therapy | | Carers | Monitoring | |
| Continue with heart failure | specialist for | | • Iron (in line | with local policies and guidelines) |
| on-going medicines manag | ement and | assessment | Transfusion | S |
| symptom control | | for support | Blood tests | |
| Ensure access to support se | | of family and | | - stopping / reducing |
| Community Specialist Pallia | uve care | carers | | ation discussions and proceed with n procedure as per implant centre |
| | | | | n procedure as per implant centre nd Advanced Care Planning |
| | | | | |
| | | | | |
| | | Dying phas | e . | |
| | | by mg pma. | ~ | and the second |
| <u> </u> | | | | |
| Refer to | Control of s | | | Shared Decision Meeting |
| f in hospital: | | e heart failure medica here is symptom mar | | ICD discussions and deactivation if not previously |
| | | | | |
| Specialist Palliative Care | | | | initiated |
| Specialist Palliative Care services | medication subcutaned | s such as diuretics (wh bus) would be used reg | hich may be | |
| Specialist Palliative Care services Heart failure specialist | medication subcutanec renal functi | s such as diuretics (wh bus) would be used reg on | ich may be gardless of the | initiated |
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Core components of care for the dying person

| Components | Measures and guidance |
|--------------|---|
| Indicators | Number of people on the supportive care register Proportion of people on the supportive care register who's symptoms are controlled Proportion of people on the supportive care register who have had Advanced Care Planning Proportion of people on the supportive care register with a DNACPR order |
| Standards | NICE QS144 (2017). Care of dying adults in the last days of life NICE QS13 (2017). End-of-life care for adults Six Ambitions – Ambitions for Palliative and End of Life Care. A national framework for local action. National Palliative and End of Life Care Partnership. Priorities for care – One Chance to get it right One Chance to Get it Right, Leadership Alliance for the Care of Dying People, 2014. Ambitions for Palliative and End of Life Care – A National Palliative and End of Life Care Partnership Mayfly Education https://www.nwcp.org.uk/nwcap/intro.html |
| Guidelines | Cheshire and Merseyside heart failure symptom control guidelines North West Coast SCN Intravenous and subcutaneous diuretics for heart failure patients in the community setting guidelines NICE NG31 – Care of dying adults in the last days of life NICE CG140 (2016). Opioids in Palliative Care: Safe and effective prescribing of strong opiods for pain in Palliative Care of Adults NICE NG142 (2019). End of life care for adults: service delivery North West end-of-life model good practice guide Clinical practice summaries |
| Competencies | Pallaborative site <i>https://pallaborative.org.uk/clinical-standards-and-guidelines/</i> clinical NICE accredited management of symptoms Advanced communication skills training to enable facilitation of conversations |



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Stage 6 Care for the dying person

When uncertain recovery is recognised this may be through the use of prognostic indicators or by admission to hospital, reduction in renal function, episodes of decompensated HF. This should lead to further discussions which may include **Do Not Attempt Cardio Pulmonary Resuscitation** (DNACPR) and treatment escalation options (formerly ceilings of care) and to identify if their wishes or priorities have changed.

It is vital all communication is done sensitively and if individuals indicate that they do not wish to discuss these issues then this too should be respected. The individuals person-centred holistic plan of care should be reviewed and any changes should be communicated with consent to the healthcare professionals involved with the individual from both primary and secondary care if applicable.

It is important to include and inform the patients family and friends in discussions when a plan of care is changed with the individuals consent. Including family and significant others will help to alleviate distress at what is a very difficult time for them. Families and friends input at this stage is necessary for both the individual and for the healthcare professionals to plan for end-of-life care if the individual's condition should deteriorate.

Other issues that may need to be addressed if there is recognition of increasing decline or a period of uncertain recovery may include:

Medical Emergency Team (MET) status

Consideration should be given to the Medical Emergency Team (MET) status of the individual within the secondary care setting. Parameters should be clearly documented within the medical and nursing notes and on the NEWS chart to avoid unnecessary distress and burden to the individual and their family and friends.

Implantable Cardioverter Defibrillator (ICD)

When it is recognised that there is increasing decline in the individuals condition, if applicable ICD (Implantable Cardioverter Defibrillator) therapy needs to be reviewed as defibrillation can cause physical discomfort and emotional distress to the individual, their family and friends. Healthcare professionals have a duty of care to consider withdrawal of non-contributory therapies – and the distress caused by resuscitation measures in those near the end of life with a progressive and irreversible decline in their condition. The decision as to when to deactivate can be difficult and discussions may be appropriate through the unstable period of illness during chronic management [stage-3] or management of decompensated heart failure [stage-4] (Unstable, amber phase, increasing decline phase 2 North West EOL Model) and discussions should be had, with deactivation being undertaken prior to the deteriorating phase (North West EOL Model red phase 3 final days of life, or stage-7 Care of the dying person with heart failure).

Deactivation should be formally documented and all relevant healthcare workers involved in the individuals care must be informed, including ambulance and out-ofhours health services. Local policy should be followed.

How to arrange deactivation

The decision to withdraw ICD therapy must be made by the health care professional (HCP) in charge of the patient care in consultation with the multidisciplinary team and having first obtained a competent patient's consent. If the patient lacks the capacity to consent the HCP must consider whether there is a valid and applicable Advanced Decision in force and/or whether there is an attorney who has been appointed under a Lasting Power of Attorney (LPA) who can give consent to the withdrawal.

For deactivation, contact can be made in working hours via the ICD clinic: 0151 600 1711 / 1701 / 1714

Out of hours, an initial attempt should be made to contact the local cardiology on-call team for further advice. Alternatively please contact the SpR oncall at Liverpool Heart and Chest Hospital via the switchboard—0151 600 1616—for advice on magnet application. For emergency deactivation there are magnets around the region – they can be found on all CCUs and most hospices have several magnets that could be borrowed in an emergency.

Treatment escalation options within Primary Care

If treatment to the individual is less effective, burdensome or against the individuals wishes the treatment escalation should be discussed and clearly documented and communicated to relevant healthcare professionals. It may be necessary for a collaborative approach with primary and secondary care providers to develop an individualised Anticipatory Clinical Management Plan (ACMP) which may include a hospital admission for maximisation of therapy.



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Treatment escalation options within Secondary Care

If treatment to the individual is felt to be futile, burdensome or against the individuals wishes the treatment escalation options should be clearly documented. It should also include if the patient is for ward only care or if they are to be considered for transfer from their ward area to Intensive Care, Acute Coronary Care or the Ventilation Inpatient Centre.

Regardless of place of care communication with the wider health professionals is vital.

(e.g. NWAS, care agencies, DN, out-of-hours GP etc.)

Recognising clinical uncertainty (e.g. AMBER Care Bundle, Secondary Care)

Clinical uncertainty should be recognised and plans put into place that prepare for improvement or deterioration of the patient. Recognising clinical uncertainty is important in both primary and secondary care although tools may differ between settings.

Discharges and Transfer from secondary care

For some individuals when it is recognised that there is increasing decline or a period of uncertain recovery it may lead to discharge from the hospital environment to their chosen place of care.

It is necessary to ensure that there is co-ordination of care between both primary and secondary care settings. For those HF patients who had been recognised to be in the last twelve months of life, GP practices should be informed via the Supportive Care Template/Gold Standards Framework notification and acknowledgement made within the 'discharge' summary.

With the individuals consent, District Nurse referrals should be made for the individuals support and palliative care needs. Where the needs of the individual are complex on transfer back to the primary care setting a referral should be made to the Community Specialist Palliative Care Team or consideration of Hospice services with the individual's consent.

Third sector referrals may be appropriate and benefit patients and their families (e.g. carers trust, charitable organisations etc.).

For any discharge planning at the end of life, with the individual's consent, family and friends should be involved and be informed. Caring for an individual at the end of life can be extremely difficult both physically and mentally and where possible the challenges should be explained to the family and friends. Unfortunately, occasionally this may mean that the patients preferred place of care is not achievable due to them requiring more support than is possible in their home environment. There is a responsibility to the carers as well as the individual and open and honest discussions about fears and anxieties should be encouraged to avoid unnecessary readmissions or transfer between settings post discharge.

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Phase of illness

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| Start of phase 3 Dying | End of phase | NW EOL model phases and Heart Failure stages |
|-----------------------------|--------------|---|
| Death is likely within days | Patient dies | Phase 3 Final days of life Stage 7 Care for the dying person with heart failure |
| | | |



Key messages

The Five Priorities of Care are part of a National Framework which should be developed with the individual and those important to them when they are recognised as likely to be dying. *They are:*

Recognise – this possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Communicate – sensitive communication takes place between staff and the dying person, and those identified as important to them.

3 Involve – the dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants

Support – the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible

5 An individual plan of care – which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion

https://assets.publishing.service.gov.uk/government/ uploads/system/uploads/attachment_data/ file/323188/One_chance_to_get_it_right.pdf

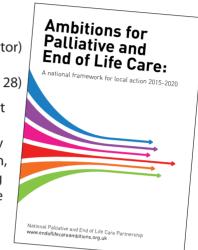
Ambitions for Palliative and End of Life Care – supporting people in the last weeks of life

All approaches regarding palliative and end-of-life care should reflect *Ambitions for Palliative and End of Life Care: A national framework for local action 2015–2020* and the six key principles as indicated below.

| Each person is seen as an individual and |
|--|
| Receives fair access to care |
| We maximise comfort & wellbeing |
| Care is coordinated |
| All staff are prepared to care |
| Each community is prepared to help |
| |

It is important that you have considered the following when in communication with the person and those important to them:

- Preferences and possibilities that could constitute an Advanced Care Plan
- Sensitive communication about care in the last days of life and decisions about Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders
- Ensure that if there is an ICD (Implantable Cardioverter Defibrillator) in place, it has been deactivated (see page 28)
- Ensure that all relevant Out of Hours services are made aware of any critical documentation, this may include using electronic special note notification



Care of the dying

Recognition that someone is possibly dying or likely to be dying is crucial to facilitate good symptom control this can be difficult in patients with heart failure as the disease trajectory is more uncertain.

An individual plan of care should be developed with the individual and those important to them when they are recognised as likely to be dying. Routine bloods and observations should be reviewed and the benefits and burdens considered (see note, next page).

Anticipatory prescribing to relieve common symptoms in the last weeks of life should be considered in a timely manner and individualised to avoid delay in managing distressing symptoms.



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How an individual could be supported through the dying process may have been identified through an advanced care plan. As an ongoing process the dying person should be involved as much as they want to and be in decisions about:

- The reason for the prescription of medications to relieve symptoms
- The choice available between different medications
- The route of administration for the control of symptoms
- Their preference for place of care

If the dying person does not wish to be involved in these discussions or unable to, it is important that those important to the dying person are involved in their care including discussions in relation to symptom control medications used, route, hydration and nutrition.

Symptom control in the dying person requires; holistic assessment, considered interventions and a review of the effectiveness of the intervention/s made.

Note: In the dying phase, you would not normally check renal function however, having knowledge of previous results is helpful to guide decision making regarding medications to use for control of symptoms. For example, if using morphine in patients where eGFR is less than 30 it may add to symptom burden rather than alleviate symptoms (e.g. hallucinations, myoclonic jerks) which would require further medication to control. Use clinic judgement with consideration of renal function and consider specialist advice within the NICE CG 140 Guidelines (referenced on page 27) and if unsure also seek specialist palliative advice when prescribing opiods in renal and hepatic impairment.



Care after death

Administration

- Verification/confirmation of death
- Death certificate

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- Post-death significant event analysis if necessary
- Update Supportive Care Record/ Gold Standards Framework Register/EPaCCS with date and place of death
- Inform all relevant agencies; social care, Allied Health Professional, ambulance service, OOH, Specialist Palliative Care Team, equipment store and GP
- Staff support/debrief if required
- Ensure processes are in place to obtain feedback from carers
- Ensure processes are in place to audit practice (e.g. mortality reviews, anticipatory medication, bereaved relatives survey etc.)

Care of the family

Support of family and carers

- Clear sensitive communication
- Funeral attendance if able and to include carer permission if appropriate or applicable
- Follow up bereavement assessment to those identified as important
- Referral of those identified as important to bereavement counselling services as required
- Department for Work & Pensions 011 Booklet: What to do after a death or similar

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This is the only step required by the law and can be performed by any suitable, competent health care professional.

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Additional guidance

https://pallaborative.org.uk/clinical-standards-and-guidelines/

The dual standard bereavement specification

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/bereavement-specification.pdf comprises a minimum standard that all hospitals should ensure is in place, and a gold standard of service, which should form part of the longer-term end of life strategy for the Trust.

In addition, the What To Expect guidance

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/what-to-expect.pdf

has been developed in response to feedback and aims to support staff in acute hospitals to provide the essential information for patients and their families in a timely and pro-active way.

Example bereavement leaflet here

https://www.england.nhs.uk/north/wp-content/uploads/sites/5/2018/06/bereavement-leaflet-recommendation.pdf



Appendix 1

Understanding phases of illness in heart failure and what we can do about it

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The North West End of Life Care Model—featured on the following two pages—is a model that supports the assessment and planning process for patients from the diagnosis of a life limiting illness or those who may be frail. The model comprises five phases. A Good Practice Guide identifies key elements of practice within each phase to prompt the assessment process as relevant to each setting and these can be found on each flow chart in the pathway. The model can be accessed at:

https://www.nwcscnsenate.nhs.uk/files/2414/3280/1623/May_2015_Final_NW_eolc_model_and_good_practice_guide.pdf

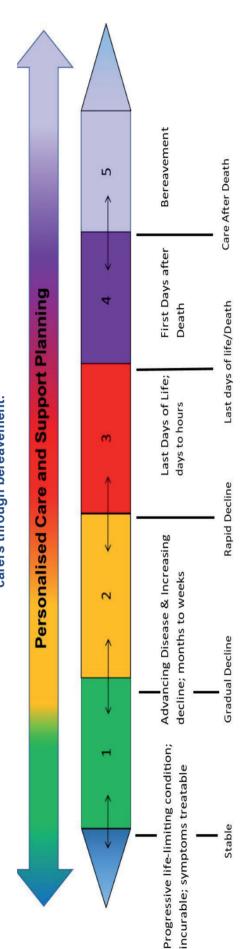
The five phases in the NW EOL care model are cross-referenced to the different stages of this pathway. When there is recognition that there is increasing decline, or the individual enters a period of uncertain recovery, the plan of care may change. With heart failure patients this may occur at any stage [or phase] of illness and changes can occur suddenly. Comorbidities should be recognised as they may impact on the patient's condition and treatment options.



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North West Model for Life Limiting Conditions

Supporting people to live well in the last years of their life before dying in the place of their choice with peace and dignity; supporting families and carers through bereavement.



Caring for a patient with life-limiting condition is about:

- Recognition and timely identification of patients with a life limiting illness (Proactive Identification Guidance)
- The person, their carers and those important to them.

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- Meeting the supportive and palliative care needs for all those with a progressive incurable illness or frailty, to live as well as possible until they die. 0
- Support in the last year (s), months and days of life and through to bereavement.

Care should be:

- ♦ Individualised and person-centred; " What matters to me and my priorities"
- Ounderpinned by shared decision making that involves the person, and those important to them;
- \diamond Education and empowerment of patients and their carers to support self-care and wellbeing
- Oclaborative, coordinated, and delivered with kindness and compassion;
- Oelivered by a competent, confident and capable workforce
- Outline of the continuity of care through good communication across all systems
- ♦ Supported through compassionate communities.

This model gives an overview of the assessment and planning process for patients with a progressive incurable illness or frailty. The Good Practice Guide on page 2 identifies key elements of practice within each phase to promote individualised, personalised care and support planning, with core principles that apply to all phases.

Specialist Palliative Care (SPC) is the total care of patients living with progressive, advanced disease and limited prognosis. The care is provided by a multi-professional analysis of complex clinical decision-making challenges applying ethical and legal reasoning alongside clinical assessment; care and support to those important to the team who have specialist palliative care training. SPC includes (but is not limited to) physical, psychological and spiritual assessment and management of symptoms; person, including bereavement care; specialist advice and support and education and training of the wider care team providing core palliative care.

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CORE PRINCIPLES (MAINTAINED FROM STABLE THROUGH TO THE LAST HOURS OF LIFE AND INTO BEREAVEMENT)

- Communication should be sensitive and unambiguous;
- Offer an Advance Care Planning (ACP) discussion; personalised care and support plan (PCSP) to be put in place; could include TEP / PPC / ADRT / LPA / Making a will;

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- Needs of those identified as important to the person are explored, respected and met as far as possible;
- Assessments should be holistic to include physical, psychological, spiritual & social aspects, rehabilitation and quality of life. Review when condition changes or as required; The principles of the Mental Capacity Act 2015 must underpin all practice; *

 - Review Prescribing; Access Specialist Palliative Care Services (with consent) when needs or symptoms are difficult to manage.

| Person identified as in rapid decline despite optimal therapeutic management of underlying medical condition (s) Exclude reversible causes of deterioration: investigate and treat as appropriate tion: investigate and prescribe anticipatory medication Pistrict Nurse referral for assessment of care needs (if at home) District Nurse referral for assessment of care needs (if at home) Enable rapid discharge to PPC/PPD (if in hospital) Monitor frequently, consider any possible crises; ensure people have contact details of who to call in time of crisis Review, or offer, ACP discussion to put PCSP in place; record EPaCCS or equivalent with consent Assessment of equipment needs Consider DS1500 Assessment of equipment needs Consider DS1500 Assessment of equipment needs Consider Continuing Health Care funding Consider DS1500 Assessment of equipment needs Consider DS1500 Refer to other specialist services as needed | MDT agree person is in the last days of life—NICE guidance Exclude reversible causes of deterioration, investigate and treat as appropriate Agree individual plan of care for the dying person, supported by local documentation, coordinated and delivered with compassion; review regularly Priorities for care of the dying person / One Chance to Get it Right Anticipatory medication prescribed and authorized for use by MDT Monitor frequently, consider any possible crises; ensure people have contact details of who to call in time of crisis Implement care of the dying nuclear any possible crises; ensure people have contact details of who to call in time of crisis Community patients: share information about expected death with OOH/NWAS, include CPR status and ACP; update EPaCCS Sensitive communication with careformily, including what to expect when someone is dying Respect and support cultural/ religious faith customs | Verification of death Medical Certification of death Respect and support cutural/religious faith customs Post death reporting: Notifiable diseases, Significant Event Analysis, Coroner referral Family, carers and those important to the person offered practical and emotional support (signpost to bereavement services) What to do after a death: https://www.gov.uk/when-someone-dies Update supportive/ palliative care record and EPaCCS with date and place of death Minely debries cCG, GP, social agencies: CCG, GP, social care, ambulance service, OOH, Specialist Palliative care record and the professionals, equipment store |
|---|--|---|
| | | District Nurse referral for assessment of care needs (if at home) Enable rapid discharge to PPC/PPD (if in hospital) Monitor frequently, consider any possible crises; ensure people have contact details of who to call in time of crisis Review, or offer, ACP discussion to put PCSP in place; record EPaCCS or equivalent with consent Consider Continuing Health Care funding Consider Continuing Health Care funding Consider DS1500 Assessment of equipment needs ICD discussion/deactivation, if applicable CPR considered/discussed; document conversation and decision Share information with OOH/NWAS, include CPR status and ACP; update EPaCCS Refer to other specialist services as needed |

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CPR—cardiopulmonary resuscitation

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Glossary

NT-ProBNP parameters

NICE clearly advocate using NT-proBNP due to its sensitivity and specificity but please note where this test is not available:

- BNP levels >100 are considered normal
- BNP levels >400 are suggestive of heart failure

Pathway implementation

The health care partnership are working on a programme to support the delivery of the pathway in 2021.

Useful tools

There are a number of commercial tools that have been developed to support and assist Primary care and practitioners to deliver and support cost effective care.

Enhance HF – a service provided by Servier and developed and delivered by Oberoi Consulting which assists CCGs to implement local and national heart failure guidelines. *www.oberoi-consulting.com*

Attend2 HF – is a clinical platform developed by Interface Clinical Services that can be used to support the identification and management of patients with heart failure and underpinned by national and international guidelines (including SIGN 147 and NICE NG106) and is used to identify patients potentially missing from the HF register based on relevant clinical codes, medication and diagnostic indicators and clinical markers. www.interface-cs.co.uk

GRASP-HF – is a free, easy-to-use tool that assists GP practices to interrogate their clinical data enabling them to improve the management and care of patients with heart failure (HF) with left ventricular systolic dysfunction (LVSD). The tool also assists with case-finding activity, helping practices to establish more accurate prevalence rates within the practice population.

https://www.nottingham.ac.uk/primis/tools/qi-tools/ grasp-hf.aspx

Useful links

- The third edition (2017) of the British Associations of Cardiovascular Prevention and Rehabilitation (BACPR) Standards & Core Components http://www.bacpr.com/pages/page_box_contents. asp?PageID=791
- Clark AL, Kalra PR, Petrie MC, et al Change in renal function associated with drug treatment in heart failure: national guidance. Heart 2019;105:904-910

https://www.bhf.org.uk/what-we-do/policy-andpublic-affairs/transforming-healthcare/heart-failurereport

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NICE impact for Cardiovascular Management report – published Feb 2021 https://www.nice.org.uk/about/what-we-do/into-

practice/measuring-the-use-of-nice-guidance/impactof-our-guidance/nice-impact-cardiovascular-diseasemanagement

- https://www.nejm.org/doi/10.1056/NEJMoa1911303
- ESC. Heart failure (2021) The impact of COVID 19 on the management of heart failure. A United Kingdom patient questionnaire study – DOI 10.1002/ehf.13209
- https://pumpingmarvellous.org/impact-of-covid-19and-heart-failure-care-in-the-uk/
- Dapagliflozin for treating chronic heart failure with reduced ejection fraction – NICE Technology appraisal guidance (TA 679) Published 24th February 2021 https://www.panmerseyapc.nhs.uk/media/2431/ dapagliflozin_hf.pdf?UNLID=800322321202132172018
- Health care Practitioners resource /education link https://www.forxiga.co.uk/
- REACH-HF (Rehabilitation EnAblement in CHronic Heart Failure) is facilitated evidence based cardiac rehabilitation (CR) and self-management programme for use at home. It comprises the 'Heart Failure Manual', a Relaxation CD, a choice of exercise (walking programme or a chair-based DVD) a 'Progress Tracker' for patients, and a 'Family and Friends Resource' for caregivers http://sites.exeter.ac.uk/reach-hf/
- One Chance To Get It Right Guidelines https://assets.publishing.service.gov.uk/government/ uploads/system/uploads/attachment_data/ file/323188/One_chance_to_get_it_right.pdf
- British Society for Heart Failure https://www.bsh.org.uk
- Isritish Heart Foundation 'Blueprint for change' heart failure report https://www.bhf.org.uk/what-we-do/policy-and-publicaffairs/transforming-healthcare/heart-failure-report
- NHS Long Term Plan cardiovascular disease https://www.longtermplan.nhs.uk/online-version/ chapter-3-further-progress-on-care-quality-andoutcomes/better-care-for-major-health-conditions/ cardiovascular-disease/
- https://www.fightingfailure.co.uk/impact-in-your-area
- Mayfly Education https://www.nwcp.org.uk/nwcap/intro.html



Abbreviations

| ADRTAdvanced Decision to Refuse TreatmentAHPAllied Health ProfessionalARBAngiotensin II Receptor BlockerBNPB-type Natriuretic PeptideCMRCardiovascular Magnetic ResonanceCPRCardiopulmonary Resuscitation |
|---|
| ARBAngiotensin II Receptor BlockerBNPB-type Natriuretic PeptideCMRCardiovascular Magnetic ResonanceCPRCardiopulmonary Resuscitation |
| BNPB-type Natriuretic PeptideCMRCardiovascular Magnetic ResonanceCPRCardiopulmonary Resuscitation |
| CMR Cardiovascular Magnetic Resonance CPR Cardiopulmonary Resuscitation |
| CPR Cardiopulmonary Resuscitation |
| |
| |
| CRT Cardiac Resynchronisation Treatment |
| DNACPR Do Not Attempt Cardiopulmonary Resuscitation |
| eGFR estimated Glomerular Filtration Rate |
| EJ Ejection Fraction |
| EPaCCS Electronic Palliative Care Coordination System |
| HF Heart Failure |
| HFpEF Heart Failure with Preserved Ejection Fraction |
| HFrEF Heart Failure with Reduced Ejection Fraction |
| HFSN Heart Failure Specialist Nurse |
| HFSS Heart Failure Survival Score |
| IABP Intra-Aortic Balloon Pump |
| ICD Implantable Cardioverter Defibrillator |
| LPA Lasting Power of Attorney |
| MDT Multidisciplinary Team |
| MRA Mineralocorticoid Receptor Antagonist |
| NWAS North West Ambulance Service |
| NE EOL North West End-of-Life |
| OOH Out of Hours |
| PCSP Pesonalised Care and Support Plan |
| PPC / D Preferred Place of Care / Death |
| RAAS Renin-Angiotensin-Aldosterone System |
| SHFM Seattle Heart Failure Model |
| SOB Shortness of Breath |
| SPC Specialist Palliative Care |
| SPR Specialist Registrar |
| TEP Treatment Escalation Plans |



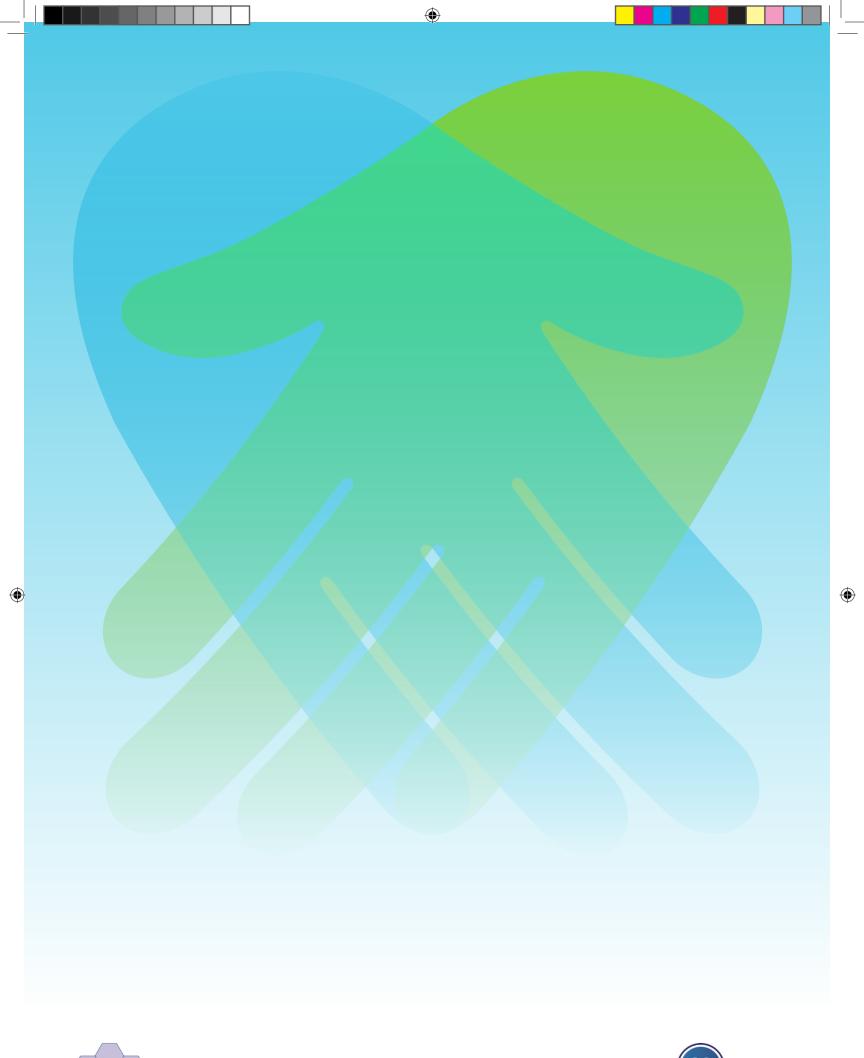
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Notes

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