

Somerset Guidance for management of End Stage Heart Failure

Last reviewed: Dec 2024

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Key contact information

Heart failure specialist nursing teams

YEOVIL 01935384884 or e-mail: heartfailurenurse@ydh.nhs.uk

TAUNTON 01823343937 (leave message if answer machine)
or e-mail heartfailureteam@somersetft.nhs.uk

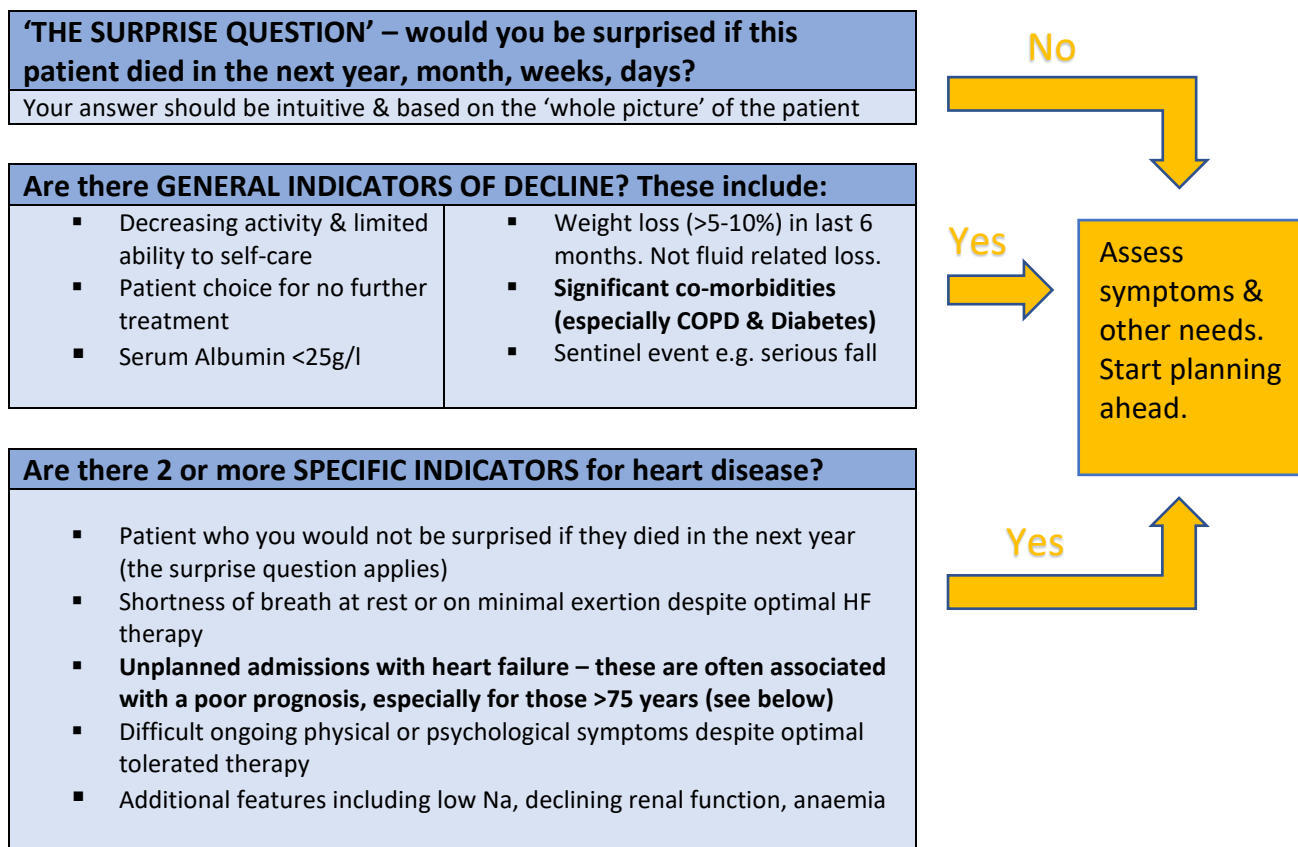
Community palliative care services

St Margaret's Hospice	01823 333822 or 01935 709480
Weston Hospicecare	01934 423900
Dorothy House, Bath	01225 722988
St Peter's Hospice, Bristol	0117 9159430

Identifying patients nearing the end of life

This can be difficult to predict, especially in heart failure where patients often deteriorate gradually but suffer acute severe exacerbations. The Gold Standard Framework (GSF) considers that patients are 'approaching the end of life' when death is likely within 12 months and suggests 3 steps for proactively identifying these patients¹.

This adapted version is a guide rather than a set of definite rules:



This may help identify when it is appropriate to adopt a palliative/supportive care approach – assessing symptoms and other needs and planning ahead.

A palliative approach does not need to be instead of active treatment – it can be alongside.

Triggers for palliative/supportive care

It can also be helpful to look for certain clinical features associated with poor prognosis and use these as a 'trigger' to think about a palliative care approach².

- **Unplanned admissions with heart failure** should be seen as an opportunity to review. They often signify progressive disease and can have an associated 1-year mortality of >30%. 1-year survival is likely to be <50% after a 3rd such admission.
- Progressive worsening of renal function
- Escalating diuretic requirements
- Persistent hyponatraemia (Na <130)
- Increasing frequency of ICD discharge or malignant arrhythmias
- Not tolerating optimal doses of disease-modifying medication (e.g. due to ↓BP)

Planning and assessing near the end of life

Identifying patients likely to be in their last year of life can enable their needs to be more effectively met and allow planning ahead.

MEDICAL NEEDS

Review symptoms and clinical situation. Contact the heart failure team for help with this if needed.

- Is escalation of heart failure treatment possible/appropriate?
- Review medications – should any be stopped or adjusted? See page 6
- Are symptoms controlled?
 - **Breathlessness** is a common symptom – see page 7
 - See page 8 for general resources on symptom management
 - Consider referral for complex or difficult to control symptoms. See page 5.
 - Are 'Just in case' medications needed in the home?
- Do they have an ICD (Implantable Cardiac Defibrillator)? Some patients have cardiac devices (ICD or CRT-D) which can deliver shock therapy and it is often appropriate to switch off this function near the end of life. Starting to consider and discuss this in advance is helpful.

ICD DEACTIVATION - detailed information on pages 11-12.

SOCIAL & CARE NEEDS

Review the patient's social situation and care needs. Possible sources of help with these aspects include Village Agents, Living Better team, Social Services. Things to consider include:

- Is equipment needed in the home or adaptations? (e.g. commode, bathroom rails)
- Would a 'Blue badge' disabled parking permit be helpful/appropriate?
- Is help needed with benefits? Citizens Advice can be helpful.
- Is an SR1 form or CHC Fast Track funding appropriate?
- Is there a need for a care package?
- Is specific carer support needed?

HELP WITH ACP is available from Marie Curie – page 10. Other resources on page 9.

PLANNING AHEAD

Advance Care Planning (ACP) is a process of planning future care and support, including for end of life care. It may need to be done in steps over time. Key aspects include:

- Who would the patient like to make decisions for them if they are not able to?
- Resuscitation status (For or not for CPR)
- Preferred place of care/death if patient has one
- Thresholds of treatment – are there particular treatments they would like to have or avoid? Would they go into hospital and in what circumstances?

Communication of this information is key. It should be recorded on the Somerset Treatment Escalation Plan (STEP) and shared electronically on the SiDeR system.

Last days and weeks of life

As a patient's condition declines there should be a review of their needs and plans made. Consider psychological and spiritual aspects as well as medical, social and care needs.

It may be hard to know when a patient is in the last weeks of life – a further decline in the indicators mentioned already may suggest this. The rate of recent decline can at times help predict the rate of future decline - if there is deterioration over weeks then the prognosis may be weeks, if deteriorating over days it may well be days.

Common signs that a patient is now dying and in the last days of life can include:

- Profound fatigue
- Becoming bedbound
- Minimal fluid intake
- Unable to swallow medication
- Poor peripheral perfusion
- Breathlessness at rest

The following may be a useful quick reference:

'CHECKLIST' IN LAST WEEKS OF LIFE
Is there a Do Not Resuscitate (DNACPR) order in place?
Has the Treatment Escalation plan been updated? <ul style="list-style-type: none">• What are the patient's preferences around hospital admission?
Have medications been reviewed again?
Are Just in Case medications available in the home?
Have care needs been reviewed?
Has ICD deactivation been discussed and actioned (if applicable)? Page 10.
Refer to specialist palliative care if complex/difficult symptoms. See below.

Referral to specialist palliative care teams

Many patients with end stage heart failure can be managed by clinical teams already known to them; this guidance is intended to help. Consider specialist palliative referral/advice:

- For complex or refractory physical symptoms (for breathlessness, see page 7)
- For complex psychological/emotional/spiritual distress related to advanced illness
- Based on the patient's needs (rather than prognosis/illness stage)

In the community referrals should be made to the local hospice-based team (see page 2 for contact details.) For inpatients please contact the hospital palliative care team.

Medication

Reviewing medication

As a patient's condition progresses, it may be appropriate to stop some drugs as the focus moves towards controlling symptoms rather than trying to extend life³. Reducing medication may decrease tablet burden and reduce side effects. These decisions should be individualised; the heart failure team can help advise. The following may help as a guide:

DRUGS WITH LIKELY SYMPTOMATIC BENEFIT. These help symptoms in the short term & are likely to be appropriate to continue for as long as the patient can take them.

e.g. Diuretics, Beta-blockers/Digoxin (in patients with AF)

DRUGS WITH POSSIBLE SYMPTOMATIC BENEFIT. These medications have prognostic benefits but can also help to keep symptoms stable. Consider stopping or reducing based upon the individual patient's symptoms. As patients become frailer they may not be able to tolerate previous doses in terms of heart rate, BP, renal function.

e.g. ACE-Inhibitors, Angioereceptor blockers (ARBs), Beta Blockers, Spironolactone, Eplerenone, ANRIs e.g. Entresto, SGLT2 inhibitors e.g. Dapagliflozin

DRUGS WITH PROGNOSTIC BENEFITS OVER THE LONGER TERM. These medications may largely be for disease prevention & not be helpful in the last weeks/days of life so consider if they should be stopped. Risks/benefits will differ between individuals.

e.g. Statins, anti-anginal medication (if less active and no recent angina.) Aspirin, anticoagulants and antiplatelet drugs – depending upon the indication for these

Medications to avoid

Some drugs are best avoided in heart failure, these include some commonly used drugs:

NSAIDS	AVOID - ↑ fluid retention & ↑ risk of heart failure exacerbation.
Steroids	Can also ↑ fluid retention - USE ONLY IF NECESSARY at lowest dose.
Cyclizine	AVOID - Strong anticholinergic effect & may exacerbate severe HF.
Amitriptyline	May ↑ arrhythmia risk & anticholinergic effect may be detrimental in severe HF - AVOID IF POSSIBLE.

Also be aware that some drugs which certainly are appropriate for use for symptom control in heart failure (including Haloperidol, Levomepromazine & Benzodiazepines) can contribute to hypotension which can be an issue in some patients.

Just in case medication

The standard Somerset 'Just in Case' medications are recommended for heart failure. Usually these are prescribed on the Somerset Palliative Care Drug Chart which also includes guidance on drugs and doses.

Breathlessness

Breathlessness is a common symptom in advanced heart failure and can be significantly distressing & disabling for patients. As well as optimisation of heart failure treatment the following are options for symptomatic management.

NON-PHARMACOLOGICAL INTERVENTIONS

These are at least as important and effective as medication. They can help patients manage their experience of breathlessness and improve quality of life. These measures include:

- Breathing techniques e.g. rectangular breathing
- Repositioning
- Techniques for managing anxiety associated with breathlessness
- Use of a hand-held fan. Directing cold air onto the face may trigger nervous system responses which alter ventilation. Explanation of this may encourage fan use.

General patient information on these approaches can be found in this useful leaflet:

<https://www.hyms.ac.uk/assets/docs/research/guide-to-living-well-with-breathlessness-general-version.pdf>

Referral for breathlessness management is an option for patients willing and able to engage with self-management strategies – contact St Margaret’s Hospice for referrals or advice.

MEDICATION FOR BREATHLESSNESS

Opioids often help reduce the subjective sensation of breathlessness, particularly when there is breathlessness at rest. They are the usual first line medication for symptoms. There is no evidence that they cause significant respiratory depression if started at low doses and titrated carefully as below. If the patient is not already on opioids then start with:

Oramorph 2mg orally as required up to every 4 hours

Note that:

- The dose may need increasing.
- In elderly or frail patients consider starting at 1-2mg.
- If already on regular opiates then consider using their breakthrough dose for pain.
- In significant renal impairment then a longer dose interval or an alternative opioid may be needed.

If breathlessness is more constant and/or persistent then a regular opioid may well be more effective than using as required. Usual starting dose is:

Morphine MR (Modified release) 5-10mg orally 12 hourly

This can be titrated – maximum dose of oral Morphine for breathlessness = 30mg/24h

Benzodiazepines may relieve anxiety and panic associated with severe breathlessness. They are less effective than opioids for shortness of breath and should generally be a second line drug option unless anxiety is prominent. They can be used in cautious combination with opioids – start with low doses and frequency and watch for sedation.

Lorazepam 0.5 to 1mg orally or sub-lingually as required 4 to 6 hourly
Diazepam 2 – 10mg orally per day is an alternative

If unable to swallow oral medication then morphine can be used subcutaneously (SC) as can Midazolam if a benzodiazepine is needed. Usual starting doses are:

Morphine 1-2mg SC as required up to every 4 hours
Midazolam 2.5 – 5mg SC as required up to every 4 hours

For persistent breathlessness then both drugs can also be given SC via syringe pump. Examples of starting doses for shortness of breath:

Morphine 5-10mg SC over 24h by syringe pump
Midazolam 5-10mg SC over 24h by syringe pump

Advice on medication is available from the hospice in the community or hospital palliative care teams for patients in hospital.

OXYGEN

Most patients with heart failure do not benefit from oxygen towards the end of life. If they are persistently hypoxic (SaO₂ <92%) with persistent breathlessness then this could be considered. Often these patients have respiratory co-morbidities such as COPD and may need a formal oxygen assessment.

Note that “Opioids are significantly better than palliative oxygen” in reducing shortness of breath in non-hypoxaemic and hypoxaemic patients - BTS guidelines on home oxygen⁴.

Selected References

1. GSF Proactive Identification Guidance (2016.) <https://www.goldstandardsframework.org.uk/>
2. Johnson MJ et al (2012.) Heart failure: from advanced disease to bereavement. Oxford University Press.
3. Sobanski PZ et al (2020.) Palliative care for people living with heart failure: European Association for Palliative Care Task Force expert position statement. Cardiovascular Research 116, p12–27. Available at: <https://academic.oup.com/cardiovasces/article/116/1/12/5544269?login=true/>
4. British Thoracic Society guidelines for home oxygen use in adults (2015.) https://thorax.bmj.com/content/70/Suppl_1/i1
5. Nottinghamshire Heart Failure Traffic Light Guidelines (2020.) Nottinghamshire Area Prescribing Committee

Other Resources

See **next page** for information on **Advance Care Planning support** from Marie Curie Talk About It.

The **Somerset end of life care** website <https://somerset.eolcare.uk/> has some useful resources including on:

- Advance Care Planning (ACP.) The Somerset planning ahead booklet is here: <https://somerset.eolcare.uk/uploads/documents/Planning-Ahead-2022.pdf>
- Benefits and finance
- Just in case medications (<https://somerset.eolcare.uk/content/jic-medication-advice>)

The SPICT (Supportive & Palliative Care Indicators tool) website has useful brief guidance on ACP [e-RED-MAP – SPICT](#)

BHF has a booklet ‘Difficult Conversations - talking to people with heart failure about the end of life’: http://www.ncpc.org.uk/sites/default/files/Difficult_Conversations_Heart_Failure_WEB.pdf

More detailed advice on symptom control:

Wessex Palliative Care Handbook (the ‘Green book’)

<https://somerset.eolcare.uk/uploads/documents/palliative-care-handbook-9th-edition.pdf>

Acknowledgements

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APPENDIX 1 - Advance Care Planning support from Marie Curie Talk About It

Referrals to Talk About It can be made on 0800 3047 412

As well as the resources listed on the previous page there is face to face support available to people in Somerset to help them with advance care planning – this is from trained volunteers from the Marie Curie Talk About It Project. More details below or at this link:

<https://www.mariecurie.org.uk/help/companions/planning-for-the-future-somerset>

“People for whom we care change in their ability to live life in the way they have done up until that point; or may not live as long as they and their loved ones might wish. At these times of natural transition, we are often party to very privileged conversations where the person tells us what is important to them. The consequences of the natural transition can lead to a crisis situation and in that circumstance, services may not respond in a way that reflects the person’s wishes, what is important to them and their family.

Creating an Advance Care Plan, through the Marie Curie Talk About It Project in Somerset is one way in which this conversation about what is important to the person and their loved one can be understood better. It is not a medical process but a conversation that explains the person and their legacy.

A trained and supported volunteer facilitates conversations. Helping the person and their loved ones articulate what is important on a human level. Families celebrate what is important alongside having support in the moments of sadness if they happen. A plan sets priorities when someone has a life limiting condition, irrespective of where they are in that journey. The process will help create legacy for those who will be bereaved, something that is known to ease the burden of loss.

Once agreed, the plan is given to the person, an electronic copy is transferred into the GP EMIS record to be available to help inform future clinical discussions, including treatment escalation plans. Agreements are in place to allow the transfer of data between Marie Curie, health and social care organisations across Somerset.

The service is active. We have found that a “warm referral” from a trusted person, who understands the benefits of the process, is the most effective introduction. The service will accept anyone you think will benefit. All that is needed is the patient’s name, address, telephone number, NHS number (if known) and date of birth when you phone 0800 3047412 or email lat.mccompanionservice@nhs.net ”

APPENDIX 2 – ICD Deactivation

Heart failure patients may have a cardiac device and some of these require review when a patient approaches the end of life.

Simple pacemakers or a Cardiac Resynchronisation Therapy- Pacemakers (CRT-P) do not require deactivation as their function is to prevent bradycardia only. If there is uncertainty about the type of device then please contact the heart failure or arrhythmia nurses to clarify.

Implantable Cardioverter Defibrillator (ICD) or Cardiac Resynchronisation Therapy-Defibrillator (CRT-D) devices have the ability to deliver a shock in ventricular arrhythmias (VF or VT.) Towards the end of life, the physical and psychological harm caused by such shocks may well outweigh the benefits and there should be a review as to whether the defibrillator requires deactivation.

Discussions should usually be started in advance of the time that the device actually needs deactivation. Waiting until the last days of life to raise the subject is usually not appropriate. There should be an open discussion between the patient, next of kin and cardiologist. Ideally this should take place whilst the patient is able to be involved in the decision-making process. The decision remains the patient's; if the patient lacks capacity the clinicians have a duty to act in the 'best interests' of the patient.

Guidelines recommend that the issue of deactivation should be discussed prior to device implantation but patients with devices are often not aware of this issue.

When discussing the expectations of deactivating the ICD the following should be made clear:

- Once deactivated, the device will not provide lifesaving therapy in the event of ventricular arrhythmia
- Turning off device will NOT cause death
- Turning off the device is not painful
- The ICD will continue to provide bradycardia pacing if the patient needs it

Please see Somerset pathway on ICD deactivation on next page:

DISCUSS DEACTIVATION WITH PATIENT / CARERS AT THE FOLLOWING POINTS OF CARE.

- Prior to implantation
- Patient experiencing repeated inappropriate activations from ICD
- No longer clinically appropriate or a patient wishes to deactivate
- When a 'DNACPR' decision has been made or a decision to limit treatment options that would allow a natural death, this should be recorded on the TEP chart
- Patient on EPaCCS (electronic palliative care co-ordination system) or palliative care end of life register
- Development of a life limiting condition and prognosis less than 12 months
- If conditions are met for an advance decisions document

ADVICE AVAILABLE FROM ARRHYTHMIA NURSE SPECIALISTS AT MPH
01823 343595, ANS@somersetFT.nhs.uk

DECISION TO DEACTIVATE AGREED WITH PATIENT, FAMILY OR THOSE IMPORTANT TO THE PATIENT

CONSIDER MENTAL CAPACITY ACT
<http://theportfolio.tst.nhs.uk/Policies/Mental%20Capacity%20Act.pdf>

IN HOURS MON-FRI
09:00-17:00

From outside MPH call 01823 342953 to speak to Cardiac Physiologists. Please provide:

- Patients name and DOB
- Place of patient care and telephone number
- Why deactivation is required
- Urgency
- Contact details of clinician (Tel/Bleep/Mobile)
- Any known details of device including manufacturer (if known)

Cardiac Physiologist to contact Consultant Cardiologist, preferably Dr Furniss or Dr Dayer if available. If in agreement direction for physiologists to deactivate ICD recorded in clinical notes. If YDH patient, contact Senior Nurse Cardiology or Arrhythmia Nurse to arrange deactivation and inform physiologist at MPH

Physiologist contacts place of care and organises the visit as soon as possible but within 2 working days. At visit physiologist assesses patient and may discuss further with Consultant Cardiologists at MPH.
Deactivate Device

OUT OF HOURS
IF DEATH IS EXPECTED BEFORE
NEXT IN HOURS PERIOD
17:00 -09:00 Mon-Fri
24 hours Sat, Sun and B/H

If the Doctor responsible for care feels deactivation is appropriate and urgent, discussion with patient and/or family should take place. If further advice required: please contact the duty cardiologist or St Margaret's Hospice advice line. All such conversations must be recorded in clinical notes and the Doctor is responsible for communication with relevant local nursing and care teams

Magnet applied as per 'How to use a magnet guide' and magnet application chart completed. Magnets located: MPH crash trolleys, OOH, Hospices, Emergency Response Vehicle, YDH A&E, and Community Hospitals.

Cardiac Physiologists at MPH or YDH appropriately MUST be contacted urgently on the next working day to arrange ICD programmed deactivation.

PATHWAY DEVELOPED BY THE ICD AND END OF LIFE WORKING GROUP JANUARY 2022