Palliative Care in End Stage Heart Failure Pocketbook

Contents

Palliative Care in End Stage Heart Failure

- This is a brief guide to the management of adult palliative care patients with end stage heart failure. It supersedes previous versions of the Palliative Care in End Stage Heart Failure Pocketbook. The choice of medicine and dosage remains the responsibility of the prescribing clinician.

- The dosage required by the patient will depend on a number of factors (e.g. age, weight, frailty, renal function) and these will need to be taken into account for each clinical situation.

- For patients in the last days of life refer to The Last Days of Life Symptom Control and Anticipatory Guidelines: https://www.nottsapc.nhs.uk/media/1078/end_of_life_care_guidance.pdf

- A holistic assessment of a patient needs to be made considering physical, psychological, social and spiritual aspects of symptoms. Management should aim to correct reversible causes and palliate symptoms with an irreversible cause, considering both a medicine and non-medicine approach taking care to prioritise those symptoms which are most important to the patient.

- At all stages the patient (and a legal welfare proxy or those close to patient if patient does not have capacity) should be given the opportunity to express and have taken into consideration, their preferences and wishes throughout the course of their condition.

- For further information including specific advice on doses please refer to the latest copy of the Palliative Care Formulary (PCF), online PCF subscription through www.medicinescomplete.com or British National Formulary (BNF)

- Comprehensive guidelines are available locally for the management of heart failure. These are available online: https://www.nottsapc.nhs.uk/media/1085/heart-failure-traffic-light-treatment-guidelines.pdf

Contacts:

Nottingham South and City
There are several routes into getting specialist heart failure advice in Nottingham. In addition to a patient's named cardiologist, there is a specialist heart failure team comprising three heart failure cardiologists and three heart failure specialist nurses. Prompt advice can be given through the regular MDT, email or through heart failure clinic.

Nottingham heart failure specialist consultant team:
Drs Bara Erhayiem, John Walsh and Jenny Chuen

Heart failure MDT referrals via:
Community and NUH heart failure nurse specialist team

HF team above, and on-call cardiology team, via switchboard:
Queens Medical Centre (0115 9249924)
City Hospital Campus (0115 9691169)

For non-urgent, simple, enquiries regarding patients *not known to NUH cardiology* the 'Advice & Guidance' (A&G) system can also be used.

Heart failure clinics:
If clinically appropriate, urgent 2 week wait outpatient heart failure clinic referrals can be made via 'Choose and Book'.

Community Heart Failure Nurse Specialists:
Nottingham North and West and North and East: 0300 0830000
Rushcliffe: 0115 8440504
City: 0300 131 0300 (SPA) or advice on 0115 8834733

Mid Nottinghamshire:

Consultant Cardiologist and Heart Failure lead:
Ifti Fazal contact through KMH switchboard 01623 622515

Cardiology consultant on-call:
KMH switchboard (01623 622515) On Call Bleep 630

Kingsmill Hospital Heart Failure Specialist Nurses:
Gail Moore and Lynsay Hayes
Contact 01623 676012 or 01623 622515 ext 4196
Mobile 07880084563 or Bleep 577
sfh-tr.heartfailurenurses@nhs.net

For non-urgent, simple, enquiries regarding patients not known to KMH cardiology the 'Advice & Guidance' (A&G) system can also be used.

Heart failure clinics:
If clinically appropriate, urgent outpatient heart failure clinic referrals can be made via 'Choose and Book'.

Community Heart Failure Nurse (CHFN):
Mansfield and Ashfield
Newark and Sherwood
01623 781899

Heart failure MDT referrals via:
Community and NUH heart failure nurse specialist team

Bassetlaw Heart Failure Cardiac Nurse Specialist (CNS): 01777 274422

Specialist palliative care:
Nottingham - Hayward House reception 0115 9627619 or professional only 24h advice line 07595285014

Mid/North Nottingham and Bassetlaw: Professionals advice line Call for Care 01623781899 option 2

Lincolnshire – St Barnabas Hospice 01522 511566

Community Palliative Care Nurses:
Nottingham CityCare: 0115 8834787
Greater Nottingham: 0300 0830100
Mid Notts Call for Care: 01623 781899, Option 2

Prognosis in Heart Failure

The typical illness trajectory for heart failure is a gradual functional decline with intermittent episodes of decompensation which may mean that death may appear 'sudden'.

Prognostication can be difficult and needs to be personalised with each patient.

What can also be difficult to predict is reversibility after a specific therapy is initiated, e.g. medicine combinations, pacemaker device and/or coronary revascularisation. Good communication with the heart failure team is essential so that symptomatic and/or prognostic intervention can be appropriately considered - or indeed, so that important timely reverse-titration of therapy can be advised.

Patients benefit from palliative care given alongside active care. Two of the following conditions could indicate that a patient may be included within your Palliative Care Register:

1) NYHA stage III to IV despite optimal medical therapy

2) The Surprise Question: I would not be surprised if this patient died in the next 6-12months?

3) Repeated heart failure hospital admissions:
   3 admissions in 6 months or 1 admission aged over 75 = 50% 1 year mortality

4) Difficult physical or psychological symptoms despite optimal tolerated therapy

Proactive Identification Guidance v7 (2022).pdf (goldstandardsframework.org.uk)

Clinical course of heart failure with associated types and intensities of available therapies and incorporation of palliative care.
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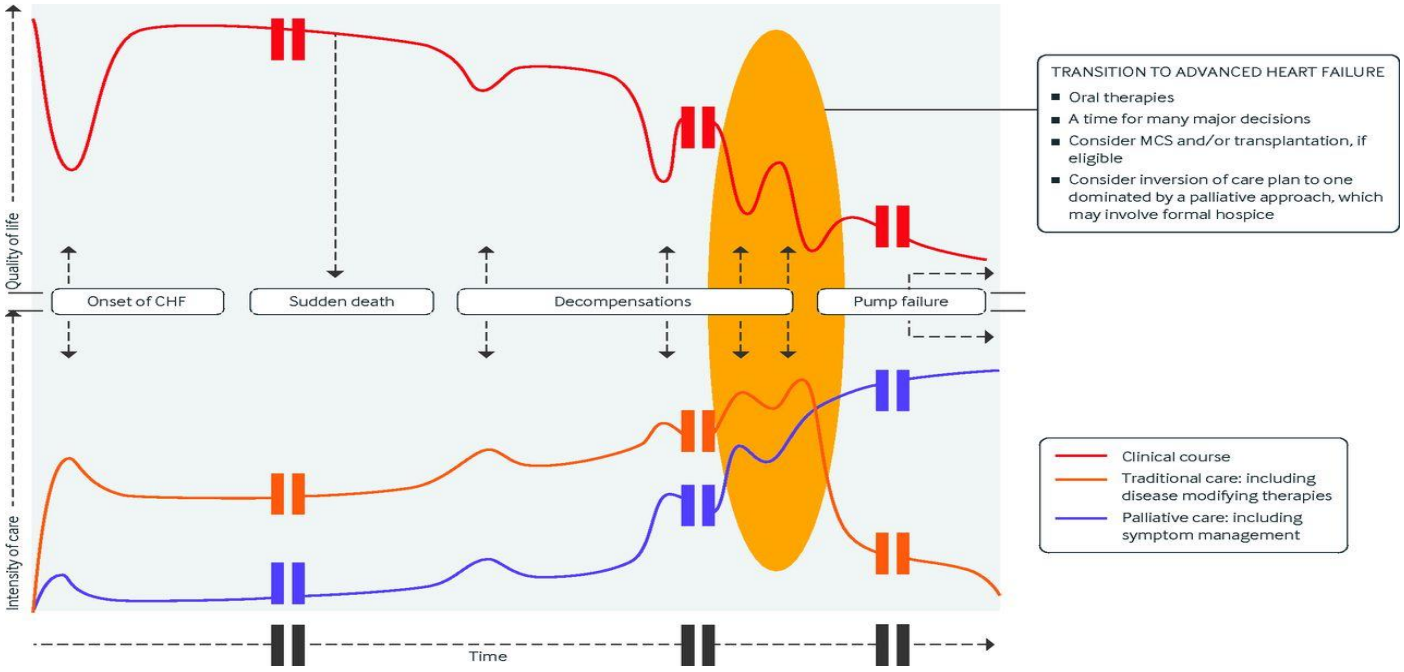


The acronym 'I-NEED-HELP' nicely summarises common triggers for referral to a heart failure specialist team:

I **I**ntravenous inotropes: previous or ongoing

N **N**YHA III/IV or persistent high BNP levels

E **E**nd-organ function: worsening hepato-renal failure

E **E**jection fraction < 20%

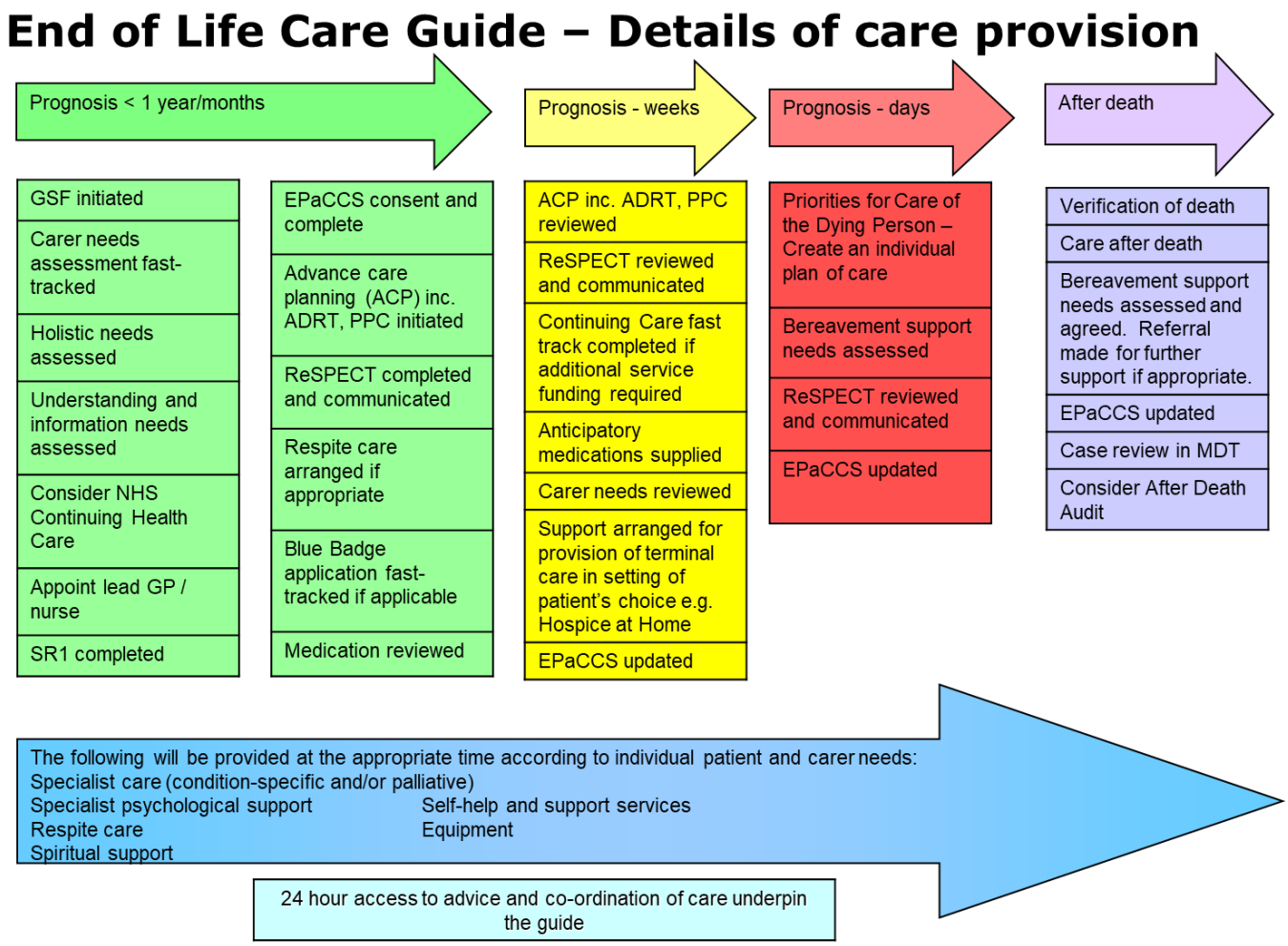
D **D**efibrillator shocks: recurrent and appropriate

H **H**ospitalisation despite HF therapy: >1 in 12months

E O**e**dema resistant to escalating multiple diuretics

L **L**ow systolic BP ≤90 with high heart rate

P **P**rognostic medications; progressive intolerance of medical therapy



Diuretic therapy

Diuretic therapy is an important reliever of breathlessness by reducing intra-cardiac pressures and helps reduce discomfort of peripheral, pitting oedema caused by venous congestion. It is commonly the first, and then final, heart failure therapy to be prescribed. Diuretic resistance and escalating dose requirements is usually more prevalent the more advanced heart failure becomes due to a variety of pathophysiological mechanisms.

A careful balance needs to be struck between iatrogenic hypotension/dehydration from over-diuresis, symptomatic electrolyte disturbance and worsening renal function. Worsening renal function and acute kidney injury can occur from inappropriately high doses of diuretic and intra-vascular fluid depletion. However, in advanced heart failure it is more common that worsening renal function is due to increasing venous pressures and poor perfusion (amongst other mechanisms) and therefore there is a need for escalating diuretic doses. Hyponatraemia is commonly caused by dilutional effect but can be a side-effect from diuretic therapy and/or marker of advancing heart failure.

If a patient remains clinically fluid overloaded with combination of peripheral oedema, breathlessness, pulmonary oedema and/or raised jugular venous pressures then escalating diuretic therapies are frequently warranted in attempt to relieve symptoms. In the presence of reduced renal function, higher doses are usually required to achieve a urinary output.

Fluid and dietary salt restriction

The practice of routine salt and fluid restriction is widespread but can be a contentious subject in heart failure practice. Patients commonly feel more unwell with thirst with strict restrictions imposed. There is no high-quality evidence that fluid and salt restriction in advanced heart failure has an overall benefit regarding symptoms and outcome and so patients should be made more comfortable with relaxation of 'rules' for oral intake.

Diuretic dosing

Loop diuretics

Furosemide: Starting dose 40mg OD. with usual maximum dose 120mg BD

Bumetanide: Starting dose 1mg OD. with usual maximum dose 3mg BD

Dosing considerations:

- 40mg furosemide = 1mg bumetanide
- Furosemide is available in liquid formulation
- Bumetanide is available in liquid formulation however is very expensive; tablets will crush (off label)
- Rarely a cause of hypotension in *congested* cardiac failure
- Avoid taking later in day/evening to reduce nocturia
- Higher doses than above can be given with heart failure team input
- Needs continued review for down-titration if congestion controlled
- Bumetanide and furosemide should not be combined

Thiazides

Bendroflumethiazide: 2.5mg to 5mg one to three times per week

Metolazone: 2.5mg to 5mg one to three times per week

Dosing considerations:

- Useful adjunct in resistant congestion despite loop diuretic +/- MRA
- Metolazone only available via unlicensed import via hospital prescription
- Profound diuresis can occur as a loop diuretic adjunct
- Diuresis most effective if taken 3-4h after loop diuretic i.e. lunchtime dose

- Frequency per week guided by heart failure team
- Needs frequent U&Es to check for hypokalaemia or hyponatraemia

Mineralocorticoid antagonists

Spironolactone:	12.5mg to 50mg OD. if with ACE-i/ARB/ARNI 50mg to 200mg OD. without ACE-i/ARB/ARNI
Eplenerone:	Second line to spironolactone, seek advice.

Dosing considerations:

- Rarely a cause of hypotension in *congested* cardiac failure
- Useful to adjunct with loop diuretics that are causing hypokalaemia
- Avoid in eGFR <30mL/min unless under specialist supervision
- U&E monitoring for hyperkalaemia or hyponatraemia
- Eplenerone can be used if spironolactone causes gynaecomastia

In selected ambulatory patients' intravenous furosemide on the heart failure day-case unit at NUH is an option. Case-by-case discussion with the NUH Heart Failure team for referral.

Subcutaneous Furosemide:

Seek advice from your palliative care unit where the patient wishes to remain at home at the final days of life. Subcutaneous furosemide may be an option. This is an off-label route however is accepted practice in palliative medicine as stated in the Palliative Care Formulary.
- Start with same dose as patient taking PO. Use 1:1 conversion.
- The maximum furosemide given in any PRN is 20mg (2ml).
- Infuse higher doses over 24h in a CSCI. Note the maximum dose that would fit in a 30ml syringe driver is 220mg/24hrs.
- Furosemide should not be mixed with other medicines in the CSCI, if further dilution is required sodium chloride 0.9% is recommended; do not mix or dilute with glucose solutions or other acidic fluids.

Breathlessness

Consider causes other than heart failure e.g. infection, COPD anaemia, pulmonary embolism

Medicine treatment

- For breathlessness at rest start with small doses of immediate release morphine 1.25-2.5mg PRN up to BD then if necessary titrate up slowly up to 4hrly PRN over the course of 1 week.
- The dose could be increased at weekly intervals if necessary by 30-50%. Generally small doses suffice with a total of 10-20mg/24h, rarely more. Usual maximum dose 30mg/24h. In COPD maximum dose <30mg/24h.
- If dose stable consider switching to m/r.
- In patients taking morphine for pain a dose of 25-100% of the 4 hrly analgesic dose (the breakthrough dose) may be needed depending on the severity of the breathlessness. For co-existing renal impairment/failure use lower dose morphine/oxycodone initially and reduce frequency to BD or TDS depending on response. If significant renal impairment (GFR<30) may need other opioids – consult a specialist palliative care team, fentanyl may be recommended. Consider prophylactic laxatives and anti-emetics when commencing strong opioids.
- For anxiety. Reduce the dose if the patient becomes drowsy due to medicine accumulation.

  Lorazepam 0.5–1 mg SL/PO BD and PRN. If necessary, increase to 2-4mg/24h.Tablet can also be dissolved in a few drops of water and 1ml placed buccally.

  Diazepam 1-2mg PRN up to TDS, increase if necessary to 15-20mg/24h in divided doses. Reduce the dose if the patient becomes drowsy due to medicine accumulation.
- Bronchodilators if co-existing asthma or COPD
- Oxygen – if hypoxic (Sao2< 92% in chronic lung conditions or <94% if no chronic lung condition) and other treatments ineffective, starting at 2L/m and continuing at this concentration if co-existent COPD. Consider use of nasal specs. Monitor for signs of hypercapnia e.g. nausea, morning headaches, drowsiness, tremors, confusion. Reduce flow rate or stop if any of these are present. Review effect and only continue if beneficial.

  Any registered health care professional can complete order forms available from www.bochealthcare.co.uk HOOF A is submitted from the site. The IHROM (initial home oxygen risk mitigation form) and HOCF (home oxygen consent form) need to be completed and attached to medical record.

Non-medicine treatment

- Electric fan blowing across face is beneficial in reducing sense of breathlessness
- Repositioning, breathing retraining and lifestyle adjustment physiotherapy and occupational therapy
- Anxiety management, psychological support, complementary therapy (discuss with community heart failure specialist nurses about local availability)

Pain

Try to avoid NSAIDs because of fluid retention, nephrotoxicity and gastrointestinal effects.

Morphine prescribing

- Usual starting dose is immediate release morphine 2.5mg four hourly, titrate slowly; reduce dose and frequency in renal impairment if using morphine or oxycodone and titrate every 48 hours or more. If significant renal impairment (GFR<30) may need other opioids – consult a specialist palliative care team, fentanyl may be recommended.
  Anticipatory medication guidance at end of life in renal failure can be found at https://www.nottsapc.nhs.uk/media/1078/end_of_life_care_guidance.pdf

- The dose for breakthrough pain is equivalent to the four hourly dose i.e. 1/6 of the total 24h dose

- 50% of patients experience nausea it is usually transient and improves in 5-7 days Prescribe an anti-emetic e.g. metoclopramide 10mg tds for prn use during the first week or prescribed regularly if the patient has had nausea with weak opioid. Haloperidol and levomepromazine would be other options.
- Laxatives are necessary at least PRN, e.g. senna

Nausea and Vomiting

Try to identify the cause and treat appropriately.

Caution is required with anti-emetics given risk of QT interval prolongation and ventricular arrhythmia. Risk particularly increases with a QTc > 500ms and/or in known prolonged QT disease. In the presence of any bundle branch block, pacemaker or ectopics, QTc prolongation is frequently incorrectly measured on automatic ECG machines and specialist opinion advised for measurement/advice. In advanced heart failure, the risk-benefit ratio should be determined on an individual basis. Uncontrolled vomiting, for example, can create electrolyte disturbance that may also cause QTc prolongation.

Gastric stasis

e.g. gastric outflow obstruction, enlarged liver, constipation due to medicines:

- use a prokinetic anti-emetic e.g. metoclopramide 10mg PO TDS – QDS or CSCI 30-40mg/24h and 10mg PO/SC q2h usual maximum dose PO/CSCI 100mg/24h

Medicines & Metabolic

e.g. morphine, antibiotics, hyponatraemia, uraemia

- review the indication for the medicine

  Haloperidol PO/SC 0.5-1.5mg nocte and q2h prn CSCI 0.5-1.5mg/24h and 1mg SC q2h prn usual maximum dose 10mg/24h

- Levomepromazine is a second line broad-spectrum anti-emetic it can cause sedation and postural hypotension. Use low dose with caution in the elderly. Start with 3-6.25mg PO nocte or 2.5-6.25mg SC nocte. Increase if necessary.

Avoid cyclizine and hyoscine in the early stages, if possible, as may worsen heart failure however, if patient is on an individual plan of care for the final days of life these medications may be considered

Constipation

Prevention is better than cure!

Almost all patients prescribed an opioid will require a regular laxative.

Consider doing a PR if bowels not opened ≥3 days or if patient reports rectal discomfort or has diarrhoea suggestive of faecal impaction with overflow.

Dose schedule for senna: if not constipated generally start 15mg at bedtime, if already constipated 15mg morning and bedtime. If no response titrate every 24-48h gradually to a maximum 30mg tds.

Dose schedule for bisacodyl: if not constipated generally start 5mg at bedtime, if already constipated 10mg at bedtime. If no response titrate every 24-48h gradually to a maximum 20mg tds.

If maximum tolerated dose of senna/bisacodyl is ineffective, add a faecal softener, then titrate as necessary, e.g. macrogol 1 sachet each morning or lactulose 15ml od-bd

If stimulant laxative causes bowel colic, divide daily dose into smaller more frequent doses or change to a faecal softener.

During titration and subsequently: if ≥3 days since last bowel action/impaction and laxatives ineffective give suppositories e.g. bisacodyl 10mg and glycerol 4g together or micro-enema.

If these are ineffective, administer phosphate enema and possible repeat the next day.

Avoid ispagula husk as requires a significant fluid intake for effectiveness. When using macrogol should not take >2 sachets in one hour.

If paraplegic, frail, debilitated:

May need to continue rectal measures on regular basis in addition to oral laxatives.

Aim for regular evacuation of normally formed faeces every 1-3 days.

For advice on doses please consult the PCF or contact your local specialist palliative care centre.

Psychological Issues

Make a holistic assessment to address underlying issues and consider formal psychological therapies.

Medicine Treatment

- Depression
  Avoid tricyclic antidepressants and venlafaxine in view of cardiotoxic side effects.

  First-line
  Sertraline 50mg OD.

  Second-line
  Mirtazapine 15-30mg nocte alternative especially if nausea, poor appetite or sleep are associated problems.

- Anxiety and Panic
  Sertraline 25mg OD. for 1 week then increasing to 50mg OD.

  Lorazepam 0.5-1mg SL up to 4mg/24h panic attacks or
  Diazepam 1-2mg PO TDS PRN

- Night Sedation
  Correct contributory factors if possible: pain, delirium, depression, obstructive sleep apnoea

  Consider sleep hygiene.
  Zopiclone 7.5mg PO at bedtime (3.75mg initially if elderly or frail) or

  Temazepam 10-20mg PO at bedtime or

  Lorazepam 0.5-1mg SL at bedtime

Fluid retention

Peripheral oedema usually effects the lower limbs, genitalia and sacrum. It is uncommon for it to affect the upper body in congestion from heart failure alone. If affecting the upper body, it is important to check that hypoalbuminaemia not the cause/contributory.

If diuretics not achieving benefit at 'usual' maximum or in difficulties with combinations, then refer to and get advice from the heart failure team.

Medicine Treatment
Covered in 'diuretic dosing' in previous section.

Non-medicine treatment

- Pruritus/dry skin – aqueous cream + 1% menthol
- Light compression bandaging – input from DN, lymphoedema or tissue viability nurse
- Scrotal support for scrotal oedema
- OT assessments – need to adjust expectations of patient and carer.
- Social worker – services at home

Medication Review

Patients are often on numerous medicines. When it is felt the patient may have 'weeks' to live rather than 'months' it is appropriate to down-titrate medications that have little prognostic benefit and/or are not contributing to active symptom control.

Below gives a guide to the importance of individual medicines in symptom control.

Medicines to consider continuing in short-term	Weigh up advantages / disadvantages of discontinuing medicines	Medicines to consider discontinuing
Diuretics Symptomatic arrhythmia therapy Anti-coagulation in metallic valves or active DVT/PE/thrombosis	ACEi /ARB/ARNI Beta-blockers Aldosterone antagonists SGLT2 inhibitors Digoxin in sinus rhythm Ivabradine Anti-anginals	Anti-coagulation for thromboprophylaxis Anti-platelets Statins Anti-hypertensives

→ Decreasingly important for symptom control →

Implantable Cardioverter Defibrillator (ICD)

An open discussion around the issue of deactivation and documentation should occur at the earliest opportunity with the patient with end-stage heart failure and their family/carer. If the patient lacks capacity decisions should be made in line with the Mental Capacity Act 2005. The heart failure team should be involved in the discussion and decide where deactivation, if required, should happen. Pacemaker elements to devices are left active to assist with symptom control when the defibrillator components are deactivated.

Indications for discussing deactivation of an ICD:

- Patient request in advanced disease
- Device therapies inappropriate in the dying phase with patient potentially receiving shocks with jolting and pain
- Following withdrawal of anti-arrhythmic medicine therapy
- While an active DNACPR-order/ReSPECT form where CPR attempts not recommended is in place
- A patient has generated an advance decision to refuse treatment specifying that they do not want the ICD active

Points of discussion may include:

- ICD Integral to general decision on cardio-pulmonary resuscitation
- Withdrawal will not result in immediate death, but the 'safety net' provided by the device will no longer apply
- Deactivation is achieved using an external programmer and is not painful
- Multi-organ failure associated with electrolyte disturbance may be pro-arrhythmic and result in device discharge
- ICD shocks are painful and inconsistent with symptomatic care
- If patient changes mind, can be reactivated
- ICD generators need to explanted if cremation is being considered

At NUH and KMH: ICD deactivation can be requested via the HF team or the existing cardiology consultant (if under active follow up). Out of Hours contact the on-call cardiology consultant. Emergency temporary deactivation can be achieved by placing a magnet over the ICD device site on the patient's skin and taping down. This is usually in the left or right upper chest. Some patients have a sub-cutaneous device in the left axilla. The magnet will deactivate the shock function but not pacemaker function. The magnet needs to be kept in position to deactivate the ICD including after death.

Patient information: https://www.bhf.org.uk/informationsupport/heart-matters-magazine/medical/icds-and-end-of-life/icd-deactivation-faqs#:~:text=Occasionally%2C%20your%20doctor%20will%20need,in%20charge%20of%20your%20care.

The Final Days

Identifying palliative heart failure patients who are approaching their final days can be a challenge, as many episodes of decompensation improve with medication. This is important in the following patient groups:

- Multiple admissions with no identifiable reversible precipitant
- On optimal treatment with increasing congestion
- Deteriorating end-organ function
- Failure to respond to appropriate changes in medicines
- Sustained hypotension

The Priorities for Care for the Dying Person including an individualised plan of care is used for patients who are thought to be dying by the multidisciplinary team. The guide ensures that everyone is working towards the goal of allowing a patient a peaceful and dignified death and that the needs of carers and those important to the patient are also met during and after death. This can be accessed via EPACCS red page. ReSPECT forms should be reviewed and EPACCS updated.

Abbreviations

ACEi	Angiotensin Converting Enzyme
ARB	Angiotensin II Receptor Blocker
ARNI	Angiotensin Receptor Neprilysin Inhibitor
ACP	Advance Care Plan
ADRT	Advance Decision to Refuse Treatment
AND	Allow Natural Death
CHF	Chronic Heart Failure
CSCI	Continuous Subcutaneous Infusion
DNACPR	Do Not Attempt Cardiopulmonary Resuscitation
EMAS	East Midlands Ambulance Service
EoL	End of Life
EPaCCS	Electronic Palliative Care Co-ordination System
GSF	Gold Standards Framework
KMH	Kings Mill Hospital
MDT	Multidisciplinary Team
MRA	Mineralocorticoid antagonist
NUH	Nottingham University Hospitals NHS Trust
NYHA	New York Heart Association
OOH	Out of Hours
PCF	Palliative Care Formulary www.palliativedrugs.com
PO	Per os, by mouth
PPC	Preferred Priorities of Care
ReSPECT	Recommended Summary Plan for Emergency Care and Treatment
SC	Subcutaneous
SL	Sublingual

BD	twice a day
OD	once daily
om	every morning
on	at bedtime
PRN	as required/needed
QDS	four times a day
stat	give immediately
TDS	three times a day

Working Group

This document was reviewed by the Nottingham and Nottinghamshire ICS EOL Programme Board in November 2020 and ratified in January 2021 and by The Area Prescribing Committee in March 2021.

Dr Christina Sharkey, Macmillan GP Facilitator, Nottingham CityCare Partnership

Dr Bara Erhayiem, Cardiologist, Clinical Lead for Heart Failure, NUH NHS Trust

Dr Bisharat El-Khoury, Consultant in Palliative Medicine, Hayward House

Dr Alpna Chauhan, Consultant in Palliative Medicine, John Eastwood Hospice

Dr Rebecca Robinson Consultant in Palliative Medicine, John Eastwood Hospice

Miriam Quinn Specialist Heart Failure Nurse, Nottingham CityCare Partnership

Helena Shores, Specialist Clinical Pharmacist, Cardiac Services, NUH NHS Trust

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