Leeds Palliative Care Network

Symptom management guidelines for patients with advanced heart failure

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Introduction

These guidelines have been prepared to help healthcare professionals manage the care of patients with advanced heart failure (HF). Symptom management and palliative care are applicable to all patients with heart failure. However, the emphasis of these guidelines is on patients with advanced disease (NYHA Class IV). It is important to ensure that there are no reversible causes for the patient's persistent symptoms and that cardiology treatment has been maximised.

The guidelines should be used in conjunction with national and local guidelines for management of heart failure and with local and national guidelines on general palliative care (see resource section page 26).

If any healthcare professional feels unable to manage any aspect of the patient's care alone at any stage, it is important that advice and support can and should be gained from a specialist (Cardiologist, Heart Failure Nurse Specialist, Consultant in Palliative Medicine, Palliative Care Team).

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Breathlessness

Dyspnoea is a major and distressing symptom of late-stage HF.

Ensure the patient's breathlessness cannot be improved by further changes in HF therapy

Assess for other correctable causes (e.g., chest infection, new atrial fibrillation, pulmonary embolism, anaemia). Check concordance with HF medication

A plan for managing acute breathlessness can be helpful for the patient, family and carers
http://www.chestmedicine.co.uk/Breathless/Breathlessness_crisis_plan_July2020.pdf

Non-Pharmacological Management

- Breathing training, useful resources available at Patient Information Hub - St Gemma's Hospice (st-gemma.co.uk)
- Exercise including walking aids
- Explore fears and concerns
- Psychological support – appreciating impact on lifestyle
- Anxiety management and education re management of panic attacks
- Relaxation
- Complementary therapies
- Portable or hand held fan directed onto the face

If patient reports daytime tiredness/insomnia and waking at night with gasping (or spouse/carer reports apnoea) consider sleep apnoea. This can be managed with non-invasive ventilation using continuous positive airway pressure (CPAP) however, not all patients will tolerate this. Specialist advice should be sought.

Pharmacological Management

- **Sublingual GTN Spray 1-2 sprays under the tongue PRN.**
  Contraindicated in severe aortic stenosis. May cause dizziness, especially if pre-existing hypotension.

- **Longer acting nitrates**. **Usually isosorbide mononitrate 30-120mg MR OD.** May be helpful for Paroxysmal nocturnal dyspnoea (PND). Important to provide at least 8 hours of nitrate-free period in each 24 hours day.

- **Opioids**
  Oral morphine modified release 5mg twice daily with concurrent prescription of **a laxative** (see constipation page 11) is advised as benefits are greater at steady state. Titrate by 5mg b.d. every 7 days according to effective and adverse effects or a dose of 15mg b.d. is reached. Patients who do not respond to this dose (30mg oral morphine equivalent a day) are unlikely to do so with a higher dose. See Opioids for Breathlessness in Advanced Disease Breathlessness – Leeds Teaching Hospitals, NHS Trust (chestmedicine.co.uk)

  Renal impairment. eGFR < 50 and > 20 mL/min. Continue to use

morphine but titrate more slowly and monitor closely for adverse effects. If eGFR < 50 mL/min and concerns about adverse effects from morphine use **oxycodone** (maximum 20mg daily). If eGFR < 20 mL/min consider low dose **transdermal buprenorphine** – seek advice.

- **Benzodiazepines** may help anxiety associated with breathlessness or during panic attacks, however may cause confusion and falls so use with caution. **Sublingual lorazepam 0.5-1mg PRN (max 4mg per day) or diazepam 2-5mg ON.**

- **Long term oxygen** Breathlessness will not be relieved by oxygen if the patient has normal arterial oxygen and may not in those with hypoxia (although other problems such as confusion may be helped). If hypoxic, humidified oxygen starting at 24% should be used with caution and as a trial with a clear review looking for benefit or not. Do not exceed this concentration if coexistent COPD. Nasal cannula are often more acceptable to patients than facemasks.

Fatigue and Lethargy

This is one of the most common and difficult symptoms to treat.

Common causes are:

- Low cardiac output or postural hypotension: seek advice from Heart Failure Team re possible addition of digoxin or reduction of cardiac medications. Sometimes it is necessary to reduce medication, which is of proven clinical benefit, because hypotension and fatigue are unacceptable.
- Hypovolaemia secondary to excessive diuretics dosages: adjust diuretic dose and frequency
- Hyponatraemia: is common in advanced heart failure and often related to fluid overload and the need for higher diuretic dose. Do not adjust medication without discussing with heart failure team
- Hypokalaemia: consider adjusting ACE inhibitor, ARNI, ARB, MRA or potassium supplementation
- Hypoglycaemia: reduce or consider stopping hypoglycaemic medication. Try to avoid if possible stopping SGLT2i, target other medication first
- Anaemia: check Ferritin, B_{12} and Folate. Consider investigation/treatment(i.e., iv iron) by heart failure team
- Medication (opioids, benzodiazepines, gabapentin): review indication and doses, especially if renal function impaired
- Low mood: assess for depression and consider treatment (see page 12)
- Episodic hypoxia
- Hypothyroidism: consider checking TFTs

Non Pharmacological Management

- Maximise symptom control (breathlessness, insomnia, psychological distress)
- Encourage aerobic exercise
- Provide information on fatigue management
- Suggest keeping an activity diary and energy expenditure planning
- Consider OT assessment re lifestyle adaptation, assistive devices and coping strategies.

Pharmacological Management

Corticosteroids and psychostimulants (i.e. methylphenidate) should be avoided due to negative effects on cardiac function.

Peripheral Oedema

Peripheral oedema in HF is most commonly secondary to right heart congestion. Other causes include;

- low albumin
- chronic kidney disease
- chronic liver disease
- medication (e.g. amlodipine)
- lymphoedema

Peripheral oedema ranges from very mild, dependent ankle oedema occurring only in the evenings, to very severe associated with ascites and scrotal congestion.

Complications include:

- leg ulceration
- pressure damage
- stasis eczema
- cellulitis

General advice

- Skin care; keep skin intact, clean and well hydrated with non-perfumed emollient (see Emollients - Suggested First Line Choices (leedsth.nhs.uk)

- Encourage movement, gentle exercise and leg elevation (with the heel free from pressure).

- Review and consider stopping any potentially contributing medication e.g. NSAIDs, pregabalin, amlodipine.

- The neighbourhood team may review the need for further equipment at home, for example pressure relieving mattress, profiling bed.

Management

The objective of treatment is to relieve the symptom and prevent complications arising from it.

- First line treatment of peripheral oedema secondary to HF is diuretic therapy (see review of medication section page 16).

- Cellulitis and leg ulcers may need treatment with antibiotics for a prolonged period until resolution. Low grade infections can worsen the severity of HF.

- Consider Aqueous cream + 0.5% menthol to reduce itch (see itch page 15).

- If the patient has unstable HF seek advice from cardiology before considering compression hosiery or bandaging.

Dry Mouth

Look for and address reversible causes;

- excessive diuretic dosage
- medication (e.g. anti-cholinergic drugs)
- oral thrush (treat according to local guidelines)
- oxygen therapy (if oxygen is indicated ensure it is humidified see page 3)

Management

- Frequent sips of unsweetened drinks
- Encouraging patient to brush teeth with fluoride containing toothpaste
- Ice crushed/ice pops
- Sugar free chewing gum or boiled sweets to stimulate saliva
- Saliva stimulating tablets
- Artificial saliva substitute (e.g. saliva-orthana lozenges)

Please consult local mouth care guidelines for additional information.

Cough

Productive Cough

Consider the usual causes of cough;

- chest infection
- worsening pulmonary oedema
- exacerbation of COPD

Non-Productive Cough

- ACE Inhibitor. Cough can begin some time after commencement, therefore consider withdrawing ACE inhibitor for at least 1 week even if patient has been taking it for some time. Consider replacing with angiotensin receptor/neprilysin inhibitor (e.g. Entresto) under specialist guidance (cardiology or community cardiac service). Angiotension Receptor Blockers (e.g. "Sartan") can be considered third line. If BP is low, simply try withdrawing ACE Inhibitor

- Fluid overload/pulmonary oedema

- GORD – especially if nocturnal cough. Consider therapeutic trial of a PPI

Pharmacological Management

- If difficulty in expectoration **Nebulised Sodium Chloride 0.9% 2.5ml-5ml maximum QDS** The amount of sodium chloride is so small that it will have no clinical consequence

- Cough suppressants for dry cough
  - **Simple lintus 5mls TDS-QDS**
  - **Codeine linctus 15-30mg PRN maximum QDS**
  - **Low dose Oramorph PRN** (**1-2.5 mg every 4 hours as tolerated**). May also help with breathlessness and pain. Always consider use of prophylactic laxatives when commencing opioids (see breathlessness page 2)

Pain

Pain is often multi-factorial.

Assess possible causes including;

- Angina – optimise anti-anginal medication
- Hepatic pain caused by congestion - consider oral nitrates or offloading excessive fluid.
- Musculoskeletal pain (osteoarthritis) Use of a standard analgesic ladder is appropriate for this pain. Paracetamol alone is often effective. **Systemic NSAIDS should be avoided if at all possible as they may worsen HF**. Topical NSAIDs are safer (although they are absorbed if used in large quantities) and may be effective.
- Gout is also common and often due to diuretic treatment. For an acute attack, **Colchicine** is the treatment of choice. Avoid NSAIDs. To reduce the likelihood of further episodes, consider starting **allopurinol** (using lower doses in those with renal impairment) 1-2 weeks after an attack has settled.

Management

- If a strong opioid is required start with **morphine sulphate modified release 10-15mg BD** with **oramorph 2.5-5mg PRN (maximum 6 doses in 24 hours, do not repeat within 1 hour)** for breakthrough pain.

- If renal function is markedly impaired (GFR <30 mL/min) or with rapidly deteriorating renal function consider an alternative opioid such as **oxycodone modified release 5-10mg BD with immediate release oxycodone 1.5-3mg (maximum 6 doses in 24 hours, do not repeat within 1 hour)**.

- **TENS machines** should be used with caution in the presence of implantable cardioverter defibrillators and should be discussed with a cardiologist first.

Nausea and Vomiting

Patients with advanced HF may have multiple causes of nausea and vomiting.

Treat reversible causes where possible.

- Digoxin toxicity is more likely when renal function is impaired, or with hypokalaemia

Consider minimising environmental factors i.e. reduce strong food smells, small portion sizes.

Prescribe anti-emetics according to the most likely cause

Severe HF and persistent nausea or vomiting can result in poorer absorption of oral drugs**.** Consider non oral routes of administration (e.g. subcutaneous) see page 16.

Cause	**Common symptoms**	**First Line Drug Stat Dose**	**24-hour range**
Gastric stasis e.g. ascites, engorged liver	Early satiety Large volume vomit Hiccups	**Domperidone 10mg PO** **Metoclopramide 10mg PO/SC**	30mg PO 30-60mg PO/SC
Chemical e.g. medication uraemia	Constant nausea Small volume frequent vomits	**Haloperidol 500micrograms PO/SC**	1-5mg PO/SC
2nd line or multifactorial		**Levomepromazine 2.5-6.25mg PO/SC**	6.25-12.5mg PO/SC

Avoid **cyclizine** as this may worsen heart failure.

Some of the drugs recommended have the potential to prolong the QT interval or to act as an anti-cholinergic. However, in the doses recommended these effects are minimal and the drugs are appropriate in the symptom management of patients with advanced disease.

Weight Loss

Patients with HF may have a poor appetite and lose significant amounts of weight. Poor appetite is exacerbated by breathlessness, fatigue, oedema, medications, renal impairment and depression. Address these if possible.

There are currently no specific evidence based nutritional guidelines so these recommendations are based on best practice.

- Dietary advice. Patients may be following previous cardio-protective (low fat or "diet" foods/drinks) or no added salt. Give permission for the patient to eat as much or as little of whatever they want. Encourage small frequent meals and snacks. If they are struggling with the palatability of a no added salt diet, it can be relaxed at this stage to improve intake.
- Family expectations relating to food intake – give permission re food intake as above.
- Patients may need assistance with shopping and cooking.
- Vitamin supplementation is generally not recommended as there is no evidence of benefit.
- Consider stopping statins in patients with a prognosis of months as they confer no benefit.

Local information leaflets may be helpful for patients and families.

Constipation

May be caused by;

- reduced intake of fluids and food
- diuretics
- calcium channel antagonists
- immobility
- opioids

Management

- Aim for a regular bowel movement, without straining, every 1–3 days
- Encourage fluids/fruit
- Relieve contributing factors if possible
- Start treatment with a stimulant laxative
    - **senna 15mg ON**
    - **titrate to a maximum dosage of 15–30mg TDS**
- If colic is a problem add an **osmotic laxative (macrogol) or a surface-wetting laxative (docusate)**
- Consider rectal interventions if bowels have not moved in 3 days despite oral laxatives (see local guidelines)
- **Prescribe laxatives routinely when commencing opioids.**

Lactulose is commonly prescribed as a stool softener but causes abdominal bloating in many patients and is therefore not the softener of choice**.**

Macrogol (i.e. movicol, laxido) is considered high in sodium and a maximum of two sachets a day is recommended. If the volumes of macrogol is difficult to take see advice about alternatives.

Anxiety and Depression

Anxiety

General management of anxiety

1. Review any poorly controlled symptoms e.g. pain, breathlessness.

2. Exclude metabolic causes of anxiety e.g. hypoxia, hypoglycaemia.

3. Review medications which may cause increased anxiety (e.g. corticosteroids, over the counter medications (those containing caffeine, decongestants, antihistamines) or motor restlessness (akathisia) (e.g. haloperidol and metoclopramide).

4. Check for abrupt discontinuation of certain substances (e.g. alcohol, nicotine, sedatives, clonidine).

5. Give the patient opportunity to talk openly about their concerns. Correct any misconceptions.

Specific management

- Discuss the nature of anxiety and possible treatments. See www.mindwell-leeds.org.uk/

- If prognosis short (days to weeks) offer a benzodiazepine
    - **Diazepam 2-10mg bedtime or lorazepam 0.5-1.0mg BD**

- If prognosis is months and there is marked functional impairment offer either
    - Referral for individual high-intensity psychological intervention (CBT or applied relaxation), or
    - **Medication e.g. sertraline 25-50mg OD, titrated to maximum dose of 100mg daily**

    - Note all SSRIs can initially exacerbate anxiety; start low and consider a concurrent benzodiazepine for the first few weeks.

Pregabalin should not be used first line but may be helpful in patients who have not responded to a SSRI.

Depression

Is common in patients with heart failure. Differential diagnoses include;

- sadness as part of a grief reaction
- adjustment reaction to events
- generalised anxiety disorder
- delirium if impairment of consciousness

Non pharmacological management

- Actively enquire about the patient's concerns and feelings

- Provide information on the nature, course and treatment of their illness
- Consider referral for specific psychological treatments e.g. cognitive behavioural therapy
- Involve psychosocial professionals

Pharmacological management

Avoid tricyclic antidepressants in view of cardiotoxic side-effects.

Consider;

- **Citalopram 10mg OD** increasing to 20mg after 1 week
- **Sertraline 50mg OD** increasing to 100mg after 4 weeks
- **Mirtazapine 15-30 mg ON** especially if nausea or poor appetite. Considered to be less sedating at 30mg than at 15mg.

Insomnia

Establish contributory factors such as;

- Anxiety and depression
- Breathlessness
- Delirium
- Difficulty with positioning
- Nausea
- Obstructive sleep apnoea
- Pain

Paroxysmal nocturnal dyspnoea (PND) is the symptom of waking in the night with shortness of breath. This occurs when fluid redistributes to the lungs whilst the patient is lying in bed preventing adequate oxygenation. Patients who have previously experienced episodes of PND may have anxieties about its recurrence. This can have an impact on both the patient's and the carer's ability to experience restful sleep. These anxieties should be discussed and practical advice about management offered, for example:

- When there are signs of fluid overload, an afternoon or early evening dose of diuretic, and an evening dose of a long acting nitrate, may be beneficial (see breathlessness page 2).
- **Sublingual GTN Spray 1-2 sprays under the tongue** can give immediate, short term relief (avoid use in severe aortic stenosis).
- Back raiser, raising the foot of the bed or a profiling bed may be helpful if sleep is disturbed by slipping down the bed.

Non pharmacological management

- Sleep hygiene measures
- Relaxation and anxiety management

Pharmacological management

Temazapam 10-20 mg ON
Lorazepam 0.5-1 mg ON
Zopiclone 7.5 mg ON (3.75mg initially in elderly or frail)

If insomnia is associated with nausea, or if benzodiazepines do not work, consider **haloperidol or levomepromazine at night.**

Itch

Itch is commonly due to dry skin or uraemia but consider other correctable causes;

- Examine the skin for localised causes e.g. dermatitis, scabies
- Hyperphosphataemia
- Iron deficiency anaemia
- Thyroid disease
- Recent changes in medication especially antibiotics
- Opioids can cause itch but not commonly (consider switch to alternative if itch started after commencement of morphine)

Non pharmacological management

- Apply emollient regularly, at least twice daily see Emollients - Suggested First Line Choices (leedsth.nhs.uk)
- Avoid soap and use moisturising soap substitute
- Avoid overheating including prolonged hot baths

Pharmacological management

- Hyperphosphataemia – **oral phosphate binder** (Hyperphosphataemia in Adults (leedsth.nhs.uk)

- Ureamia – **low dose gabapentin 50-100mg ON** (maximum dose 300mg ON dependent on renal function)

- Idiopathic - consider
    - **Sedating antihistamine, at bedtime or regularly e.g. chlorphenamine 4mg ON (4mg QDS)**
    - **Sertraline 50-100mg OD**
    - **Mirtazapine 15-30mg ON**

Review of Medication

General principles

Regular review of patients' medication is essential for patients thought to be in the last months of life. The rationale for any changes should be discussed with patients and carers.

The aim of medicines may be to improve HF prognosis or to improve symptoms and/or functional capacity. However, many medications that have been proven to improve prognosis may also have a symptomatic benefit e.g. ACE inhibitors/ ARNIs, beta blockers, MRAs and SGLT2 inhibitors.

1. Weigh up the benefits versus the adverse effects e.g., unwanted effects of digoxin can occur when drug levels are within the therapeutic ranges; excessive vasodilation can lower BP and induce pre-syncope or severe fatigue.
2. Drugs primarily prescribed to improve prognosis with no symptomatic benefit may be discontinued e.g. statins.
3. Drugs primarily to improve symptoms or function (e.g. diuretics, digoxin, vasodilators) should be continued. Adverse effects should be monitored closely and dosages adjusted accordingly.
4. Drugs that improve prognosis and may also have symptomatic benefit should be continued if the patient is able to manage them and the benefits outweigh any adverse effects. Adverse effects should be monitored closely (e.g. symptomatic hypotension) and dosages adjusted accordingly.
5. Use the lowest doses of drugs necessary to produce the desired symptomatic benefits rather than targeting for "trial-proven doses".
6. The frequency and doses of drugs should be given to cover sufficient durations. Inadequate regimen resulting in frequent break-through symptoms can interrupt restful sleep and may be distressing. Medication to prevent paroxysmal arrhythmias should cover the full 24 hour day, whereas medication to control exertional angina can be limited to cover the physically active parts of the day. Similarly, long-acting nitrates can be taken before bedtime, instead of the usual morning dosing, to alleviate nocturnal dyspnoea or decubitus angina.
7. The route of administration needs careful consideration:

    a) The least invasive methods of delivery (i.e. oral route) are preferable.
    b) The route of administration should also be balanced against efficacy of absorption e.g. oral administration may be inappropriate due to swallowing difficulties or poor absorption due to gut oedema. Similarly, many patients with HF have gross oedema or poor dermal perfusion which may make subcutaneous or transdermal administration problematic.
    c) Personal and cultural sensitivities should be respected.

Specific medicines to help symptoms

Diuretics

Fluid retention and pulmonary congestion can be profoundly distressing hence diuretics are necessary medication for late-stage HF therapy.

The aim of diuretic therapy in HF is to maintain fluid balance, i.e. to ensure fluid intake equals output. It is important to remember that diuretic dosages may need to be reduced if there is reduced fluid intake, to prevent dehydration and renal failure. Features of hypovolaemia or dehydration include dry mucosa, reduction of skin turgor, postural hypotension. If fluid intake is significantly diminished (e.g. nausea, vomiting, swallowing difficulty, sedation), then the diuretics may even need to be discontinued for periods of time.

In HF patients with peripheral oedema, it is not necessary to aim to remove all traces of oedema by aggressive diuretic therapy. The margin between complete absence of peripheral oedema and dehydration is very narrow. Only symptomatic oedema or oedema associated complications (e.g. ulceration) require more aggressive diuretic therapy.

Principles of diuretic dosing:

- Avoid nocturnal diuresis that will disturb sleep, unless the patient already has an in-dwelling urinary catheter.
- Repeated split doses are more effective than a once daily dose.
- For patients with stress incontinence, the use of longer acting diuretics (e.g. torasemide) and in some cases MRAs may be better tolerated and improve compliance.
- Loop or thiazide diuretics can cause hypokalaemia and hypomagnesaemia. Adding or increasing potassium sparing diuretics (i.e. MRAs) is more effective and better tolerated than potassium supplementation
- Stopping aspirin may enhance diuresis
- Bed rest will enhance diuresis
- For patients with poor oral absorption of oral diuretics consider an alternative route
    - intravenous
    - if IV access difficult, or not wanted, or on balance is unlikely to provide further benefit, a closely monitored trial of subcutaneous diuretic infusion can be trialled at home
    - if IV or SC diuretic is not wanted or appropriate, then changing from oral furosemide to a better absorbed drug, such as bumetanide, is worth trying.

The use of combination diuretics:

- Loop diuretics and metolazone in combination are particularly potent and may be used sparingly to "kick-start" diuresis, especially when IV administration is not an option. Risk of hyponatraemia
- Loop and thiazide diuretics combination is similar but may not be as powerful.
- When starting combination therapy, it may take 48 hours or more before the maximal effects are seen.
- Spironolactone (or eplerenone) should usually be co-prescribed to reduce the risk of hypokalaemia.

Beta Blockers

In some patients with poor heart rate control beta blockers can improve breathlessness.

Digoxin

In selected patients with severe systolic dysfunction, digoxin may improve symptoms and function. It is particularly effective in atrial fibrillation but may be helpful in sinus

rhythm as well. It is often worth a therapeutic trial. Toxic effects (such as nausea) are more likely to be seen when renal function is impaired, or with hypokalaemia, even low doses.

Nitrates

Nitrates have little role in treating congestion as nitrate tolerance develops very rapidly and they are poorly absorbed after oral administration. However, they can be helpful in patients with acute symptoms, such as in paroxysmal nocturnal dyspnoea (PND), when administered sublingually.

Nitrates may help in patients with angina, but better drugs are available. The rapid development of tolerance means that a nitrate-free period of 8 hours out of 24 is necessary, so nitrates are probably best used to address specific problems, such as nocturnal angina or frequent PND, when a long acting nitrate given at night may be helpful.

Morphine

See breathlessness (page 2).

Principles for the withdrawal of cardiac drugs in advanced heart failure

The burden of administration versus the benefits should be considered for each individual. Further information is available in LTHT deprescribing guidance (Medicines Optimisation Guidance for Adult Patients with a Limited Prognosis (leedsth.nhs.uk)

Cholesterol lowering drugs (e.g. statins) can usually be the first to be discontinued because they have no symptom relieving properties.

Anti-platelet and anti-coagulant therapy should be considered on an individual basis, based on risks and benefits. Antiplatelet agents are typically given to lower the risk of ischaemic events (angina/MI). If symptoms are stable and the prognosis is poor from the HF, these need not be continued. Anticoagulants (warfarin, DOACs) are mainly given to lower the longer-term stroke risk. The decision to stop these requires careful discussion.

Anti-anginal drugs can be discontinued if the patient is asymptomatic, especially with reduced physical activity

Anti-arrhythmic drugs can lower blood pressure and can contribute to fatigue. If symptomatic tachycardias are present, or a patient has poor heart rate control or a drug such as a beta blocker is also helping angina symptoms, it may be best to continue. Digoxin does provide some symptom relief so may be continued, unless swallowing medication is a problem or side effects such as nausea develop.

ACE-inhibitors/Angiotension receptor blockers / **Angiotensin receptor-neprilysin inhibitors (ARNIs e.g. Sacubitril with Valsartan / Entresto)** If possible continue as they do provide some symptomatic relief. However, stop if symptomatic hypotension or the quantity of medications taken is troublesome.

Diuretics should be continued as long as possible, including loop diuretics (can have in liquid form), thiazides and MRAs.

Withdrawal of Devices or ICDs

An ICD is an implantable cardioverter defibrillator. The purpose of the ICD is to monitor the heart rhythm and respond to arrhythmias using several key functions:

- Administration of defibrillation shocks to terminate ventricular fibrillation (VF) or ventricular tachycardia (VT).
- Anti-tachycardia pacing (ATP) to terminate ventricular tachycardia.

An ICD often, but not always, has anti-bradycardia pacing to prevent the heart rate dropping below a specified value.

An ICD is sometimes combined with a Cardiac Resynchronisation Therapy device (CRT-D). CRT is used in patients who exhibit ventricular dyssynchrony and symptoms of heart failure. This device paces both ventricles in an attempt to resynchronise their activation.

The decision to deactivate an implantable defibrillator can be difficult for patients and their relatives and should be addressed on an individual basis. Patients are often anxious about deactivation and have a perceived dependence on the device.

Principles:

- Eventual withdrawal of ICD care should be discussed prior to initial implant in all patients.
- ICD patients should be encouraged to express their concerns especially in relation to their mode of death and shocks.
- It is appropriate but not always essential to deactivate ICD's in patients with end stage HF. Not all patients will have a tachyarrhythmia in the terminal phases but it is humane to try and avoid multiple shocks, ultimately the patient's wishes should be respected if they want to continue active resuscitation attempts.

When the patient's prognosis is thought to be weeks, it should be explained:

- Deactivation of their ICD device does not mean that they will die imminently.
- The ICD may have been of value in prolonging their life in the past, it may no longer be in their best interest for them to receive painful and often traumatic shocks.
- Pacing functions including Cardiac Resynchronisation Therapy can be left active with the defibrillator function turned off.
- The Resuscitation Council have a helpful patient information leaflet

https://www.resus.org.uk/sites/default/files/2020-05/CIEDs%20leaflet_patients.pdf

Deactivation should be considered and discussed at the same time as do not resuscitate decisions are made. It is incompatible that a patient should have an active ICD but otherwise not be for resuscitation.

There should be liaison with the Cardiac Devices Clinic along with the supervising electrophysiologist/device physician when deactivation is being considered.

A ring magnet will deactivate an ICD whilst it is held directly over the device. It can be used to turn off an ICD in an emergency. The magnet should be taped over the ICD to

stop it functioning until the device can be deactivated. Coronary care units, cardiac physiology departments, hospices and ambulances should all have a ring magnet and will be able to advise.

When a patient dies with an active ICD Cardiac Devices Clinic should be notified as the device requires deactivation before removal by mortuary or undertaker staff. Relatives should be made aware that cremation is not possible with an ICD in situ.

Further information on deactivation, including contact details, for patients in hospital and in the community can be found on Leeds Health Pathways

Guidelines for the Decision to Withdraw Implantable Cardioverter Defibrillator (ICD) Therapy (leedsth.nhs.uk)

Financial Benefits

Patients with later stages of HF are eligible for:

- Attendance Allowance if over 66 years.
- Personal independence Payments if aged between 16 and 66 years.

If the prognosis is thought likely to be less than 12 months applying under "special rules" will ensure the application is treated as a priority. GP or hospital doctor or nurse specialist should complete the SR1 form to enable this application. This applies to patients of any age and the SR1 form exempts them from any further health tests.

If patients need help to complete these forms or further benefits advice, local help is available from citizen's advice bureaux, Age Concern, Welfare rights.

Free Prescriptions. A patient is eligible for free prescriptions if they are unable to get out without the help of another person. Contact local pharmacy for advice.

Last Days of Life

It is often difficult to diagnose the dying phase of HF. A proportion of patients with HF will experience sudden death. However, others deteriorate more slowly.

It is important to exclude any easily reversible causes for a sudden deterioration. Common precipitants include:

- an episode of ischaemia
- onset of an arrhythmia
- noncompliance with medication
- concurrent infection

Also, review the diagnosis and check there is no treatable cause for the heart failure (e.g. valvular heart disease). Consider discussion with cardiology to ensure there are no other management options.

The following often indicate that a patient has reached a prognosis of weeks or less:

- Increasing frequency of hospital admissions (despite optimum tolerated medication) with no identifiable reversible cause
- Worsening renal function and resistant hyponatraemia
- Diuretic resistance - failure to respond within two to three days to appropriate change in diuretic or vasodilator drugs
- Sustained hypotension
- Increasing fatigue
- Becoming largely nursed to bed

Try to establish consensus within the team about a patient's condition.

If the chances of recovery are uncertain, but the patient appears "sick enough to die", share this with the patient and/or family.

As a patient becomes weaker and has difficulty swallowing, it is important to discontinue non-essential treatment and interventions, only continuing those which will provide symptomatic benefit:

- Unless the patient has a poor oral intake, diuretics should be continued. In general all other cardiac medications can be withdrawn.

- Essential medications such as analgesia, anti-emetics and anxiolytics can be given subcutaneously, often as an infusion via syringe driver with extra stat doses as required.

- Discontinue procedures that will not change management such as venepuncture and checking of temperature, BP.

- The inappropriateness of CPR should already have been established. If this has not been done it should be agreed and documented.

- Discuss stopping intravenous hydration with patient and family (it may worsen fluid retention and there is no clear evidence that it helps symptom control).

- Continue regular assessment of symptoms and adjustment of medication if symptoms are not adequately controlled.

- Provide psychological support to patient and family. Clear but sensitive communication is paramount.

- Offer to arrange spiritual care according to the patient's cultural and religious beliefs.

For further guidance please see Symptom Management Guidance in the Last Days of Life
Last Days of Life (leedsth.nhs.uk)

Referral to Specialist Palliative Care Teams

All patients with advanced HF require a supportive/palliative care approach with the aim of maximising their quality of life. This requires shared decision making between the patient, their carers and healthcare professionals. In most cases, the professionals already caring for them will be able to continue providing adequate care. Guidelines such as these are designed to help them in this.

However, if the professionals caring for a patient are not able to manage a problem satisfactorily then referral to a specialist palliative care service should be considered. , People requiring specialist palliative care referral usually have one of more of the following problems:

- Difficult communication issues such as coping with uncertainty, prognosis
- Difficulties in determining future care wishes
- Complex physical or psychological symptoms despite optimal tolerated therapy.
- Carers with high risk of bereavement difficulties.

Resources

For full prescribing information please refer to the current edition of the British National Formulary or Summary of Product Characteristics *www.bnf.org.uk and www.emc.medicines.org.uk*.

Further prescribing information for use in Palliative Care please refer to
Wilcock, Howard, Charlesworth. Palliative Care Formulary Edition 8 (PCF 8)
Palliative Care Formulary | MedicinesComplete

Medicines Management | Leeds Palliative Care Network

LTHT deprescribing guidance (Medicines Optimisation Guidance for Adult Patients with a Limited Prognosis (leedsth.nhs.uk))

Gold Standards Framework, www.goldstandardsframework.nhs.uk

British Heart Foundation ICD deactivation at the end of life: Principles and practice
ICD deactivation at the end life: Principles and practice - BHF

Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death Guidance from the Resuscitation Council (UK), British Cardiovascular Society and National Council for Palliative Care
Publication: Cardiovascular implanted electronic devices in people towards the end of life, during cardiopulmonary resuscitation and after death | Resuscitation Council UK

Supportive Palliative Care in Heart Failure - what may matter to you.
072175-V2-Pumping-Marvellous-Palliative-Care-Guide-1.pdf (pumpingmarvellous.org)

Cardiac Supportive Palliative Care Guidance
Patient info and HCP resources — British Society For Heart Failure (bsh.org.uk)

Glossary

ARNI	Angiotensin receptor/neprilysin inhibitor
BD	Bis Die / Twice daily
BP	Blood pressure
COPD	Chronic obstructive pulmonary disease
DOAC	Direct oral anticoagulant
GORD	Gastro-oesophageal reflux disease
HF	Heart failure
IV	Intravenous
MRA	Mineralocorticoid Receptor Antagonist
ON	Omni nocte at night
OT	Occupational therapy
PND	Paroxysmal nocturnal dyspnoea
PPI	Protein pump inhibitor
QDS	Quarta die sumendum / to be taken four times a day
SGLT2i	Sodium-glucose co-transporter-2 inhibitors
TDS	Ter die sumendum / to be taken three times a day
TFTs	Thyroid function tests

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