

MANAGING SYMPTOMS IN PATIENTS WITH HEART FAILURE AT THE END OF LIFE

Contents

MANAGING SYMPTOMS IN PATIENTS WITH HEART FAILURE AT THE END OF LIFE.....	1
1.1. Scope.....	2
1.2. Introduction	2
1.3. Anxiety and depression.....	3
1.4. Breathlessness	4
1.5. Constipation.....	7
1.6. Cough	7
1.7. Dry Mouth	8
1.8. Fatigue and Lethargy	9
1.9. Insomnia	10
1.10. Itch (Pruritus)	11
1.11. Nausea and Vomiting.....	12
1.12. Pain	12
1.15. Peripheral Oedema.....	14
1.16. Weight loss, anorexia and cachexia in end stage disease.....	14
1.17. Financial benefits.....	15
1.18. Withdrawal of Devices or ICDs	16
1.19. Review of medication.....	18
1.20. Medication for improving heart failure symptoms.....	20
a. Diuretics.....	20
b. Digoxin.....	23
c. Nitro-vasodilators.....	23
d. Morphine.....	23
e. Positive inotropic drugs.....	24
1.21. Last Days of Life	25
1.22. The five common symptoms in the last few days of life	28
1.23. Referral to The Palliative Care Team.....	28
2. CONSULTATION, APPROVAL AND RATIFICATION PROCESS.....	31
3. DOCUMENT CONTROL	32
4. DISSEMINATION AND IMPLEMENTATION	33

5.	REFERENCE AND ASSOCIATED DOCUMENTS	33
6.	APPENDICES	35

1.1. Scope

The following guidelines have been prepared to help health care professionals in Harrogate and Rural District to provide supportive and palliative care to patients with heart failure (HF) with particular regard to symptom control.

1.2. Introduction

The following is assumed:

- A full assessment of the patient's problems has been made, taking into account physical, social, psychological, financial and spiritual issues, and appropriate referrals or actions taken to address these. This should be carried out by the patient's usual attendant team, in partnership with secondary care teams: for example, by the heart failure clinical nurse specialist (CNS) the GP and community care team.
- The patient's heart failure management (including assessment and referral for consideration of cardiac resynchronisation) has been optimised and closely monitored. Some patients are unable to tolerate titration to optimal medication doses and others may make an informed decision not to pursue medical interventions.
- In the event of deterioration, reversible factors have been detected and treated.
- There has been clear communication regarding the diagnosis and plan of management between the attendant team and the patient, family and carers, and between secondary and primary care services.
- A clear plan for out-of-hours care is in place, particularly for patients with advanced disease. This can be recorded on the Electronic Palliative Care Co-ordination System (EPaCCS).
- Advice or referral is sought from the Palliative Care Team for persistent or complex problems, or for care in the last days of life if the patient's stated preference is hospice. Please see the Palliative and End of Life Care pages on the HDFT intranet and website, and the Harrogate and

Rural District (HaRD) CCG website for further information. A shared care approach is advised, although the relative inputs from cardiology and palliative care may alter as the patient deteriorates.

- It can be difficult to pinpoint when the focus of care should switch to palliation only. In these guidelines, we assume that palliative care will be given alongside continued disease modifying therapy at maximally tolerated doses (that is, ACE inhibitors, beta-blockers and mineralocorticoid antagonists): the drugs also alleviate symptoms. Other drugs (see below) should be stopped. The needs of the individual patients and their family should be paramount.

1.3. Anxiety and depression

At least one third of HF patients suffer from depression and/or anxiety. Psychological distress impacts on many symptoms, understanding of disease, compliance with medication and survival.

A full assessment of contributory factors and involvement of the multi-professional team is required to address the issue. Formal screening tools such as HADS, GAD7 and PHQ9 can be helpful in detecting patients suffering from depression and/or anxiety.

Non pharmacological approaches:

- Consider cognitive behavioural therapy
- Consider low impact exercise programmes: see <http://www.nhs.uk/Livewell/fitness/Pages/Lowimpact.aspx>
- Encourage social stimulation of available activities; may include attendance at Saint Michael's Hospice Day Therapy Unit or HF support group attendance
- Consider breathing training, particularly with regard to anxiety management

Pharmacological approaches:

Depression:

- Avoid tricyclic antidepressants in view of their cardiotoxic side-effects, unless they have been already been prescribed long-term
- SSRIs such as *sertraline 50mg daily*, *citalopram 20 mg daily* and *mirtazapine 15-30 mg nocte* appear to be 'heart safe'
- *Sertraline* is recommended as first line treatment in those with chronic physical health problems by Clinical Knowledge Summaries (see <https://cks.nice.org.uk/depression>)

- *Citalopram* has fewer drug interactions, especially with warfarin
- *Mirtazapine* may be useful if there is also persistent nausea or poor appetite
- *Trazodone* (starting at 50mg nocte, and titrated as tolerated to 200mg nocte) may be useful if insomnia is also a problem

Anxiety:

- If panic is a major feature of breathlessness, then *lorazepam 0.5-1mg* may be helpful and is absorbed sublingually. Care should be taken, however, because of increased risk of falls and memory loss with benzodiazepines.
- For persistent anxiety consider *fluoxetine 20-60mg daily (20-40mg in the elderly)* or *citalopram 10-20mg* or *mirtazapine 15-30mg at night*.
- *Diazepam 2-5 mg po nocte*. Longer acting than lorazepam so may be effective for more persistent anxiety

A Cochrane review (Simon S et al 2010) found that there was no evidence to support or refute a role for benzodiazepines for the management of refractory breathlessness, however evidence is limited. Benzodiazepines may be used if anxiety is felt to play a significant role in the breathlessness.

1.4. Breathlessness

Breathlessness is a major and distressing symptom of advanced HF. Effective management is dependent on accurate understanding of the nature of dyspnoea and the diagnosis of the mechanisms responsible. Differentiating pulmonary from cardiac causes of dyspnoea will be the first step, although overlaps between the two are not uncommon.

Acute deterioration almost always has a cause or causes. Consider:

- Chest infection
- New atrial fibrillation
- Pulmonary embolus
- Non-adherence with medication
- Ischaemia
- High salt load
- Anxiety/panic

Once it is clear that the patient's breathlessness cannot be improved by further changes in HF therapy and that there are no other correctable causes, consider one or more of the following palliative measures:

Non-pharmacological management

- Optimise rehabilitation potential with an appropriate exercise programme to address cardio-respiratory deconditioning and maintain muscle bulk
- Breathlessness management, including breathing retraining, pacing or prioritising activities and panic management for anxiety attacks. Useful resources are available at <https://www.cuh.nhs.uk/breathlessness-intervention-service-bis/resources>
- Occupational therapy to enable maximal mobility and functioning
- Psychological support: this may be provided through the clinical nurse specialist or may require another referral, for example clinical psychology service or day hospice
- Relaxation therapy
- Complementary therapies
- Hand-held fan
- If night time breathlessness is a problem due to the patient slipping down the bed then a back raiser, raising the foot of the bed mattress with wedges or even a profiling bed in the home may be helpful

If the patient reports daytime sleepiness and waking at night with gasping (or sleep partner reports apnoeic spells), consider sleep disordered breathing. A referral for nocturnal continuous positive airways pressure (CPAP) may be appropriate although CPAP is not tolerated by all patients. Central sleep apnoea presents in 50% of later stage HF patients.

Pharmacological management

- *Oxygen:*
Stable heart failure patients do not desaturate unless there is sleep disordered breathing, or a precipitating cause. The latter should be sought and treated. Breathlessness will not be relieved by oxygen in a patient with normal arterial oxygen and may not be relieved in those with hypoxia (although other problems such as confusion may be helped). Humidified oxygen starting at 24% should be used with caution and as a trial with *a clear review looking for benefit or not*. If sleep disordered breathing is present, then specialist advice should be sought. Do not exceed this concentration if coexistent COPD. Nasal specula are often more acceptable to patients than facemasks.

- **Nitrates:**
 - *GTN Spray 1-2 puffs prn.* Can be helpful in acute episodes of breathlessness. Contraindicated in severe aortic stenosis. May cause dizziness, especially if pre-existing hypotension.
 - *Longer acting nitrates. Usually isosorbide mononitrate MR 30-120 mg od. GTN patches (10-20 mg Buccal Suscard 1-3 mgs nocte)* for patients unable to swallow tablets; overnight use is beneficial in some people. **It is important to provide at least 8 hours of nitrate-free period in each 24 hours.**

- *Nebulised saline 0.9% +/- bronchodilators e.g. salbutamol 2.5 mg or terbutaline 2.5 mg prn to qds.* May be indicated if there is significant co-existing reversible airways disease. Be warned that they can cause a significant tachycardia. If co-existing angina, GTN spray should be available if using nebulised bronchodilators as angina may be precipitated. For chronic therapy, combination long acting beta agonist/long acting muscarinic antagonist (LABA/LAMA) therapy may be helpful.

- **Opioids:**
 - *Low-dose morphine sulphate oral immediate release. The initial dose is 1mg-2.5mg PRN with titration according to effect.* The possible mechanisms of action include reduction in central perception of breathlessness (similar to reduced central perception of pain), reduction in anxiety, reduction in sensitivity to hypercapnoea, reduced oxygen consumption and improvement in cardiovascular function. It is likely that the influence of different mechanisms varies in different people.
 - Unless needed for pain, do not exceed a daily morphine equivalent dose of 30mg/day. Patients who have not responded by this dose are unlikely to do so with a higher dose (Currow D et al 2011) and a study of COPD patients on LTOT showed that doses greater than 30mg/day for refractory breathlessness are associated with excess mortality (Ekström MP et al 2014).
 - Morphine is excreted renally so use sustained release preparations with caution in the presence of renal impairment. If significant renal impairment is present (eGFR less than 30mls/min), oxycodone 1-2mg may be used instead: Between an eGFR of 30 and 50, either morphine or oxycodone can be used, depending on how well the medication is tolerated and how quickly the renal function is changing. Contact the Palliative Care Team or pharmacy for further advice if needed.
 - A nocte dose may ease sleep disordered breathing and resultant nocturnal breathlessness and sleep disturbance.
 - Prophylactic laxatives are recommended and access to a suitable antiemetic, as some patients may feel nauseated initially.

- For patients who are sensitive to morphine, alternative opioids may be suitable and more advice regarding these can be obtained from the Palliative Care Team.
- *Benzodiazepines:*
 - *Sublingual lorazepam 0.5-1mg prn (max 2mg/24 hours).* The rapid onset of action makes this useful in panic attacks, but should be limited to this situation because of concerns regarding falls and cognitive impairment.

1.5. Constipation

Constipation may be caused by:

- reduced fluid and food intake
 - diuretics
 - immobility
 - opioid medication
 - calcium channel antagonists.
- Prescribe prophylactic laxatives when starting opioids
 - Unless there is a previous diagnosis such as irritable bowel disease, avoid bulk forming agents, such as ispaghula husk (Fybogel) because fluid restriction makes it difficult to drink the required daily recommended amount.
 - A polymacrogol (such as Movicol or Laxido) can be used. Senna is an alternative if volumes are difficult (starting dose 2 tablets nocte)
 - Refer to the [Guidelines on use of laxatives to manage constipation in palliative care](#)

1.6. Cough

Productive Cough:

Consider the usual causes of cough such as chest infection, worsening pulmonary oedema, exacerbation of COPD or suboptimal COPD management.

Non-Productive Cough:

- Consider fluid overload and worsening pulmonary oedema as a cause.

- Cough due to ACE inhibitor can begin sometime after commencing; therefore consider a trial of withdrawal of ACE inhibitor for at least 1 week, even if patient has been taking it for some time. Consider replacing the ACE inhibitor with an ARB (angiotensin receptor blocker).
- If difficulty in expectoration - nebulised sodium chloride 0.9% PRN. Usual dose 2.5ml-5ml.
NOTE: this dose accounts for 23mg-45mg of sodium chloride. This is then nebulised, so the whole dose is not actually received. Absorption from the respiratory tract is probable as well as from the GI tract. However, the amount of sodium chloride is so small that it will have no clinical consequence.
- Cough suppressants for dry cough:
 - Codeine linctus 5-10mls PRN to qds
 - Low dose immediate release morphine (1-2.5mg PRN) or sustained release morphine (5mg bd). This may also help with breathlessness and pain. **Always consider use of prophylactic laxatives when commencing strong opioids** (see Constipation and Review of Medication section).
- Consider other causes:
 - Gastric reflux if nocturnal- a therapeutic trial of a proton pump inhibitor may help
 - Late onset cough variant asthma
 - Nocturnal pulmonary oedema- GTN patches may help

1.7. Dry Mouth

Mouth care can make a big difference to quality of life and impact on other symptoms such as nausea and weight loss.

It may be caused by oxygen therapy (ensure this is humidified), medication, underlying oral thrush.

Assess for underlying cause, e.g. excessive diuretic dosage, opioid, anticholinergic or other drug therapy.

Consider trial of:

- Ice cubes/crushed ice/ice lollies
- Chewing gum (sugar free may reduce risk of dental caries and oral thrush)
- Fruit (be aware of potential impact upon glycaemic control if concurrent diabetes): e.g. pineapple juice (sipping or sucking pieces), orange or satsuma segments, frozen grapes

- Oral balance gel
- An artificial saliva such as Glandosane spray

N.B – grapefruit juice should be used with caution as this can interact with drugs such as statins and some calcium channel blockers (but not amlodipine).

1.8. Fatigue and Lethargy

This is one of the most common and difficult symptoms to treat. Look for reversible causes, which might include:

- Low cardiac output or low BP: Seek advice of Heart Failure Team or Cardiology about possible addition of digoxin or reduction of beta blocker, ACE Inhibitor /ARB, diuretics. Sometimes it is necessary to reduce medication which is of proven clinical benefit, because the side effects of symptomatic hypotension and fatigue are unacceptable. Care should be taken with down-titration of beta blocker /ACE inhibitor as rebound breathlessness or angina may occur.
- Hypovolaemia secondary to excessive diuretics dosages: check skin turgor, U&Es, postural hypotension and adjust diuretic dose and frequency accordingly
- Anaemia: consider investigation/discuss treatment by heart failure specialist/team – some patients benefit from I.V. iron infusion
- Hypokalaemia: check U&Es and correct any electrolyte imbalance. Sando-K is recommended for its more rapid onset compared to slow K.
- Hypothyroidism: check TFT and blood sugar
- Hyponatraemia: this is very common in end-stage heart failure and is associated with a poor prognosis. When it is symptomatic (usually when sodium falls below around 125mmol/l), specialist advice may be helpful. It is usually not helpful to reduce the diuretic dose as it will simply cause fluid retention; infusion of hypertonic saline may be helpful.
- Cardio-respiratory deconditioning: discussion with patient and carer regarding approach to pacing activities and refer for low impact exercise programme if available
- Consider lifestyle adaptation & assistance with coping strategies. Occupational Therapy assessment may be helpful.

Seek advice from /consider referral to Cardiologist/Heart Failure specialist team if in doubt as to cause. Benefit may be gained from the implantation of devices such as biventricular pacemakers.

1.9. Insomnia

This is a common but often missed symptom.

Look for contributory factors:

- anxiety and depression
- breathlessness
- reduced mobility
- difficulty with positioning
- pain
- central sleep apnoea and address as appropriate.

Paroxysmal nocturnal dyspnoea (PND) is the symptom of waking in the night with shortness of breath. This occurs when oedema fluid redistributes to the lungs whilst the patient is lying in bed and then prevents 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 addressed on an individual patient basis and practical advice about management of PND should be 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 section on breathlessness), however nocturia should be discussed. Use of GTN spray can give immediate, short term relief (avoid use in severe aortic stenosis).
- Relaxation and anxiety management
- If central sleep apnoea is the main problem, a small dose of opioid such as *Oramorph solution 1mg-2.5mg at night*, or *nocturnal oxygen therapy* may help
- Night sedation may be required: *temazepam 10mg-20mg at night*; *lorazepam 0.5mg -1mg at night*; *zopiclone 3.75mg-7.5mg at night* or *trazodone 50mg at night*. *Prescribe with caution in those taking diuretics causing nocturia: night sedation may increase falls risk.*
- If associated with nausea, *haloperidol 0.5-1.5mg at night*, or *levomepromazine 3-6.25mg at night* may be helpful.

- Disturbance due to slipping down the bed at night may be helped by a profiling bed. Other measures such as raising the mattress at the knees, using a back raiser or propped pillows may help.

1.10. Itch (Pruritus)

Pruritus (or itch) is a distressing symptom and can occur in those patients with end stage heart failure symptoms. There are a number of potential causes of itching, although the pathogenesis is not fully explained and remains complex.

Heart failure patients often have declining renal function which increases levels of urea and creatinine. Fluid overload can also cause the liver to become congested and thus affect the liver function causing an accumulation of toxins and potential cholestasis. Uraemia and cholestasis is a common cause of neurogenic itch. Some patients with heart failure may already be taking opioids for symptom control and may experience itch as a side effect of opioids – consider switching to an alternative opioid preparation. It is also worth eliminating any histamine mediated itching such as allergic type reactions to food, medication or household triggers.

Non-pharmacological strategies focus upon management of dry skin, soothe inflamed skin and prevent further acute itching episodes and skin damage.

- Bathing recommendations: reduce frequency of bathing, keep water temperature tepid, use non scented soap/gel,
- Avoid skin irritants e.g. perfume/fragranced anti-perspirant
- Wear loose clothing and cotton based garments
- Avoid extreme heat/sunlight and maintain a cool and if possible humidified room environment.

Pharmacological recommendations have limited evidence within the literature though suggestions from current clinical practice include:

- Emollients (consider aqueous cream with 1% menthol)
- SSRI such as Paroxetine
- Mirtazapine
- Ondansetron
- Antihistamine (sedating or non-sedating) can be considered if allergic/inflammatory cause is suspected
- Low dose gabapentin
- Lidocaine 2.5% cream can be used for localised areas of itching. The temporary anaesthetic effect causes sensory nerve cell numbing.

1.11. Nausea and Vomiting

Patients with heart failure may have multiple causes of nausea and vomiting including gut oedema, hepatic engorgement and renal failure.

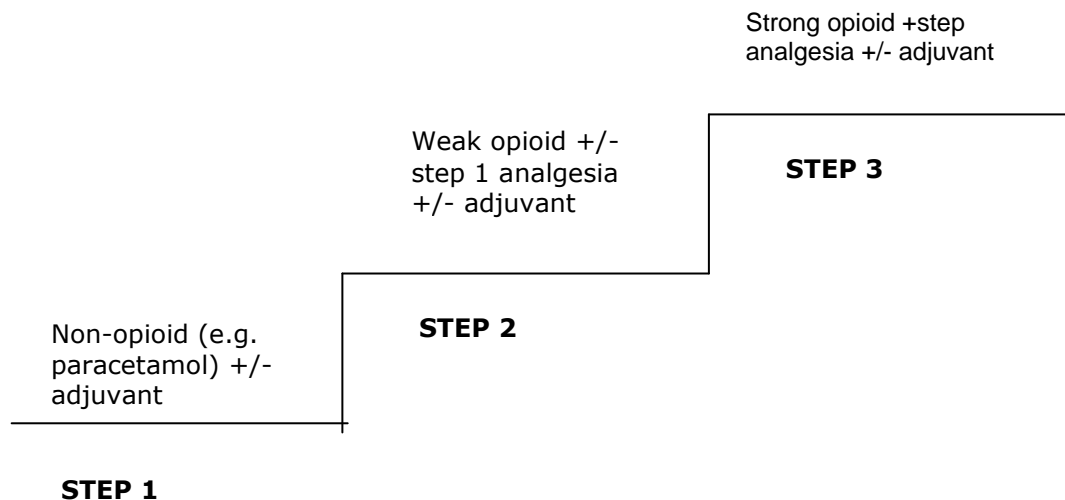
If vomiting is significant, or there is gut oedema, the oral route may be temporarily ineffective and the subcutaneous route advised, either using stat subcutaneous injections or continuous infusion via a syringe driver. When vomiting is controlled, the oral route could be tried again.

- Consider side-effects of medication as a cause of nausea and vomiting
- If nausea is constant, or there is renal impairment try *haloperidol 0.5-1.5-mg* orally or subcut injection nocte
- If related to meals, constipation, early satiety, vomiting of undigested food, hepatomegaly: *domperidone 10mg tds*
- If nausea and vomiting persists:
 - *Low dose levomepromazine 3-6.25mg po nocte or 2.5-6.25mg sc nocte*
- Avoid cyclizine as it may worsen heart failure
- Some of the drugs recommended above either 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.

1.12. Pain

Patients require a full assessment of pain, including the site, possible causes etc. Remember to consider other causes and pathologies (e.g. angina and musculoskeletal pain) in addition to HF.

- NSAIDS should be avoided as they worsen heart failure
- The World Health Organisation analgesic ladder, although developed for cancer patients, can be applied equally to patients with heart failure and is appropriate particularly for the commonly experienced musculo-skeletal pain:



WHO Analgesic Ladder

Step 1: Simple analgesia: paracetamol 1g qds (be aware, some paracetamol preparations have a large sodium load)

Step 2: Add a weak opioid: co-codamol 30/500 two tablets qds

Step 3: Strong opioid: Start dose 1mg-2.5mg qds oral morphine sulphate solution (oramorph) and titrate as necessary. Alternatively, 5mg bd modified release oral morphine can be started without using IR preparations 4 hourly initially.

Reduce dose frequency of strong opioids in renal impairment and use modified release preparations with caution. If renal function is markedly impaired (GFR <30 micromols/min, or fluctuating), contact the Palliative Care Team for advice regarding alternative opioids. (See also Review of Medication section).

- In ischaemic pain, anti-anginal medication should be optimised: beta blockers may help angina in addition to HF
- Hepatic pain may be due to engorgement, and this pain may respond to nitrates
- Gout is common. For an acute attack, colchicine is the treatment of choice. Allopurinol should be used to prevent further attacks; use a lower dose in renal failure. Although steroids are also relatively contraindicated in heart failure because of fluid retention, sometimes prednisolone 10mg daily is required to control an acute attack of gout. Careful monitoring of daily weight should alert to significant fluid retention. For mono-articular gout, intraarticular injection of steroids may be helpful.

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

1.15. Peripheral Oedema

Firstly assess whether this is due to any other cause e.g.

- hypoalbuminaemia
- liver failure
- varicose veins
- medication (e.g. verapamil, amlodipine)

Peripheral oedema due to HF is caused by right heart congestion. Complications include leg ulceration, bedsores, stasis eczema, and cellulitis. Peripheral oedema ranges from very mild, dependent ankle oedema occurring only in the evenings, to very severe associated with ascites, scrotal congestion and sub-conjunctival oedema. The objective of treatment is to relieve the symptom and prevent complications.

- Optimise diuretic therapy
- Good skin care is mandatory; Diprobase or Zerobase cream are recommended emollients
- Cellulitis and leg ulcers are common and can be managed by the community care team who can seek further advice from the tissue viability nurse specialist if required. However, persistent and painful cases, especially those complicated by infected ulceration, may need prolonged antibiotic treatment.
- Bandaging or a scrotal support may be helpful in some patients, particularly in the presence of lymphorrhoea
- If itch is a feature, then *menthol 0.5% can be added to aqueous cream*
- Pressure relieving equipment may be needed, for example a pressure relieving mattress, profiling bed

1.16. Weight loss, anorexia and cachexia in end stage disease

Patients with HF may have a poor appetite and lose significant amounts of weight. Poor appetite may be exacerbated by breathlessness, fatigue, oedema, dry mouth, drug side-effects, renal dysfunction and depression.

In early stage disease, assessment of and attention to reversible issues, nutritional assessment and dietary advice may help the patient regain weight and improve quality of life. However in end-stage disease, a metabolic syndrome of anorexia cachexia may render dietary supplementation futile and burdensome for the patient.

There is currently no specific evidence based guidance, and the following are based on best practice for end stage disease.

- Look for reversible factors and address them.

- Dietary messages can be confusing as patients may be following cardio-protective dietary advice, using low fat or 'diet' foods/drinks which are too low in energy for their changing needs. Patients who increase their nutritional intake and prevent further weight loss, or increase their 'dry' weight may have an improved sense of well-being and improved body image.
- There may be family expectations relating to food intake that can make mealtimes stressful. In general, give permission for the patient to eat small frequent meals of whatever they want. This may help with nausea and bloating.
- If the patient is struggling with the un-palatibility of a low salt diet, this can be relaxed at this stage.
- Assess the patient's need for assistance with shopping or cooking.
- Higher calorie foods can be encouraged though some patients may find this difficult as it goes against previous health advice to eat full fat products. Some patients may benefit from oral nutritional supplements, but if the patient finds them a burden they should not be insisted upon. Refer to a dietitian for advice regarding the use of prescribed dietary supplements.
- Statins should be stopped in advanced heart failure as they confer no benefit.
- Small amounts of alcohol can be used as an aperitif and appetite stimulant.

1.17. Financial benefits

Patients with NYHA grade III or IV disease may be eligible for the following:

- Attendance allowance (AA if >65 years and needs help with personal care)
- Personal Independence Payment (PIP) (if <65 years, need help getting around, help with personal care, or both)

Normally, help should be required for at least 6 months before becoming eligible, but because patients with advanced HF have a considerable likelihood of death within that time they would be eligible for application under the 'special rules' if a GP, consultant or Heart Failure or Palliative Care Clinical Nurse Specialist signs the DS1500 form.

Application packs can be obtained via the local benefits office or via the website: <http://www.gov.uk/browse/benefits/disability>

If patients need help to complete these forms or further benefits advice, local help is available from one stop shops, Citizen's Advice Bureau, Age Concern, Welfare rights etc. Home visits can be arranged via the Department of Work & Pensions which provides useful assistance through the process.

It is important to obtain a date stamped application pack as benefits granted can then be backdated to this date.

Note: A patient is eligible for free prescriptions if they are unable to get out without the help of another person. Contact GP surgery and local pharmacy for advice.

Travel abroad should only be considered with full insurance for patients with end stage HF. Difficulty may be encountered. Advice regarding suitable companies can be obtained from BACUP and the British Heart Foundation (www.bhf.org.uk/hearthealth/living-with-a-heart-condition/holidays-and-travel).

Useful resources:

The Citizen's Advice Bureau (CAB), social services, Age Concern and Carers' Resource.

1.18. Withdrawal of Devices or ICDs

Implanted defibrillators are increasingly commonplace in the management of HF and may be combined with cardiac resynchronisation therapy (CRT).

ICDs are programmed to sense ventricular dysrhythmia and deliver a shock with the aim of restoring sinus rhythm and prevent sudden cardiac death (SCD). They are associated with increased survival in patients with NYHA class I or II symptoms. However, as end stage disease approaches, the myocardium will become less responsive to cardioversion. The concern is that the patient's death will be accompanied by the ICD discharging unsuccessfully. More distressingly, successful cardioversion to sinus rhythm can be short-lived, leading to repeated conscious discharges in the time prior to the patients' eventual death. This is distressing to patient, carers and staff.

It is important to establish the patient's understanding of their ICD function and its implications. Patients may have very different attitudes to their ICD from fear of discharge to fear of its being 'taken away', not appreciating that a time will come when it will not be able to restore normal rhythm. They may also have erroneous beliefs, equating 'reprogramming to pacemaker mode' to 'immediate death' and the patient may need explanation and reassurance.

The decision to deactivate an implantable defibrillator can be difficult for patients and their relatives and should be addressed on an individual basis. Patients often report dependence on the device. (The final cause of death in severe heart failure patients is most commonly due to progressive heart failure or from tachyarrhythmia).

General principles:

- **Eventual withdrawal of ICD care should be discussed prior to initial implant in all ICD recipients.** Where this has not happened, this subject should be discussed as early as possible.
- It is appropriate to deactivate ICDs in patients with end stage HF and constitutes withdrawal of treatment. Not all patients will have a tachyarrhythmia in the terminal stage, but it is humane to try and avoid multiple shocks in those who do.
- Deactivation of the device in the community setting is problematic. It should be considered and discussed at the same time as DNACPR decisions are made and ideally be discussed if a patient is being discharged from hospital to palliative community care. Some functions can be turned off after discussion with the patient and family.
- When anti-arrhythmic medical therapy is being withdrawn patients should be aware that device activation is more likely and they may consider switching off the shock function.
- ICD patients should be encouraged to express their concerns especially in relation to their mode of death and shocks.
- There should be liaison with defibrillator clinic and specialist nursing staff along with the supervising electrophysiologist/device physician when deactivation is being considered. Local systems should be in place for deactivation in the patient who is too unwell to attend the clinic where it was inserted. Local technicians will need to know the type of device used; the patient may have a card with the make on it, or the clinic which placed the device will have a record.
- A ring magnet will deactivate an ICD whilst it is held directly over the can. It can be used to turn off an ICD in an emergency. To ensure ICD remains off, the magnet should be taped over device until it has been deactivated. Coronary care units and cardiac physiology departments (and sometimes hospices) should all have a ring magnet and will be able to advise.
- When a patient dies with an active ICD, local systems should be in place to deactivate the device before removal by mortuary or undertaker staff. Cremation cannot take place with an ICD in situ.

Some important points to explain to people about ICD deactivation:

- Deactivating your ICD will not cause death
- Once your ICD has been deactivated, if you have a heart rhythm change that could cause death, your ICD will not deliver treatment for it
- Deactivating the shock function of your ICD does not deactivate its pacemaker function
- Deactivating your ICD will be painless
- Near the end of your life your ICD may deliver shocks that are painful and distressing and are of no benefit
- If your condition improves unexpectedly or you change your mind the ICD can be reactivated
- It is best to think and decide about ICD deactivation in advance, rather than in a crisis

Discussion of resuscitation status is also advised when considering advance care planning. Please refer to the [HDFT ICD deactivation policy](#) and [DNACPR policy](#).

Useful resources:

ICD deactivation at the end life: Principles and practice – BHF publication for professionals (resource code: M106)

Deactivation of implantable cardioverter-defibrillators towards the end of life *A guide for healthcare professionals from the Resuscitation Council (UK) the British Cardiovascular Society and the National Council for Palliative Care* March 2015

1.19. Review of medication

When a patient presents with an exacerbation of heart failure, or apparent 'end stage' heart failure, it is important to exclude any reversible cause of deterioration i.e. reverse the reversible.

Common precipitants include: an episode of ischaemia; onset of arrhythmia; noncompliance with medication; concurrent infection. In these cases, treating the cause relieves the symptoms better than anything outlined below, although symptom directed treatment may be given concurrently.

In addition, it is always important to be certain that there is no treatable cause for the heart failure itself. Always review the diagnosis and be certain:

occasionally the underlying cause of heart failure is treatable e.g. valvular heart disease and haemochromatosis.

A thorough review of patients' medication is essential. For a full review of pharmacotherapy of heart failure, readers are advised to refer to standard cardiology textbooks and published heart failure guidelines. There are, however, a few basic principles specific to medical therapy for symptom management in late stage HF. It is helpful for the caring clinicians to be clear which HF drugs are to be continued or can be withdrawn.

Drugs used generally fall into two categories:

- a. Those used for prophylactic therapy or to improve HF prognosis
- b. Those providing symptom relief \pm improvement in functional capacity

The principles of continuation or withdrawal of medication for late-stage HF patients therefore consist in the following:

1. Drugs primarily prescribed to improve prognosis can be withdrawn. The rationale for these changes needs to be discussed with patients and carers. Improving prognosis is subsidiary to improving symptoms in these patients.
2. Drugs primarily prescribed to improve symptoms or function (e.g. diuretics, digoxin, and vasodilators) should be continued, but the dosages should be monitored, reviewed regularly and adjusted accordingly.
3. Dose should be selected to produce the desired symptomatic benefits, use the highest tolerated dose if a 'trial proven dose' target can't be reached.
4. The frequency and doses of drugs should be given to cover sufficient time periods. An inadequate regime resulting in frequent break-through symptoms can interrupt restful sleep and be quite distressing. For example, 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.
5. Weigh up the benefits versus the side-effects/adverse reactions – e.g. diuretics may impair renal function or precipitate gout; unwanted effects of digoxin can also occur while drug levels are within the therapeutic ranges; excessive vasodilatation can lower BP far enough to cause pre-syncope or severe fatigue.
6. The route of administration needs careful consideration:
 - a) The least invasive methods of delivery are preferable.

- b) The route of administration should also be balanced against efficacy. Oral administration may be inappropriate in patients with swallowing difficulties or in oedematous patients when intestinal absorption is often poor. Many patients with HF have gross oedema or poor dermal perfusion which may make subcutaneous or transdermal administration problematic.
- c) Personal and cultural sensitivities to some routes of administration (PR, PV) should be respected.
- d) Common sense should always prevail, e.g. if the patient is mouth breathing, a nasal prong delivering O₂ can be placed in the mouth rather than the nostrils.

1.20. Medication for improving heart failure symptoms

The key drugs to improve symptoms specifically arising from HF are diuretics, digoxin, vasodilators and inotropic agents. A brief guide is included here for the management of late-stage HF patients.

a. Diuretics

Diuretics are the first line therapy for symptoms of congestion in patients with HF. Diuretics are often necessary because a natural compensatory mechanism in HF triggers fluid retention. Fluid retention and pulmonary congestion can be profoundly distressing and hence diuretics are usually necessary medication for late-stage HF therapy.

The aim of diuretic therapy in HF is to remove any excess fluid and then maintain fluid balance, ensuring fluid intake = output. Because either side of the equation can change independently, it is important to remember that diuretic dosages may need to be reduced if there is reduced fluid intake in order to prevent dehydration and renal failure. Features of hypovolaemia or dehydration include dry mucosa, reduction of skin turgor, and 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 remove all traces of oedema by aggressive diuretic therapy. The margin between complete absence of peripheral oedema and dehydration is narrow. Only symptomatic oedema or oedema-associated complications (e.g. ulcerations, bedsores) require more aggressive diuretic therapy.

The choice of diuretics is detailed in standard textbooks and review articles. Always look out for electrolyte disturbances which can cause arrhythmias with subsequent worsening of dyspnoea.

Principles of diuretic dosing:

- Avoid nocturnal diuresis that will disturb sleep, unless the patient already has an in-dwelling urinary catheter.
- For patients with stress incontinence, the use of longer acting diuretics (e.g. torasemide) may be better tolerated and improve compliance.
- Diuretics are far more effective given intravenously than orally. This is particularly true for furosemide.
- Repeated split doses are more effective than a once daily dose.
- Continuous infusion of furosemide is probably more effective than repeated boluses to the same cumulative dose
- If intravenous diuretic is not appropriate, then changing from oral furosemide to a better absorbed drug, such as bumetanide, is worth trying.
- For people with difficult IV access, or for whom hospital admission is not wanted, and on balance, is unlikely to provide further benefit, a closely monitored trial of subcutaneous diuretic infusion may be provided.
- Loop or thiazide diuretics can cause hypokalaemia and hypomagnesaemia. Adding or increasing K⁺ sparing diuretics is more effective than K⁺ supplementation.
- Stopping aspirin may enhance diuresis
- Bed rest will enhance diuresis

The use of combination diuretics requires special mention:

- Combination diuretics can be very helpful where a patient requires very large doses of loop diuretic (more than 80mg furosemide or its equivalent twice daily), or where a patient has become apparently resistant to diuretics.
- The combination of loop and thiazide diuretics causes 'sequential nephron blockade' and is often used to 'kick-start' diuresis, especially when IV administration is not an option. In many patients, regular loop and thiazide administration is needed to control fluid retention (see "self-management" below). Some believe that metolazone is particularly effective in this situation when added to a loop diuretic.
- Combination therapy may cause an abrupt and very profound diuresis and patients' fluid balance should be carefully monitored. It is also particularly liable to upset electrolyte balance and is likely to cause hyponatraemia. Hyponatraemia may itself cause symptoms and is associated with a worse prognosis, but may be the price to be paid to control fluid retention in some patients.

- 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.

Patients with late-stage HF may become diuretic resistant with severe symptomatic congestion. Measures that may help include admission to hospital for the temporary use of inotropic drugs (via IV infusion). An alternative approach can be ultrafiltration, which can allow large volumes of excess fluid to be removed rapidly. Once the oedema has resolved, provided there is still adequate renal function, the patient may become responsive to (and be able to be maintained on) oral diuretic therapy again.

Gout is a particular problem with high dose diuretic therapy. Non-steroidal anti-inflammatory drugs should usually be avoided to treat an acute attack as they cause fluid retention and worsen renal function. Colchicine is helpful in relieving symptoms, and there should be a low threshold for starting treatment with Allopurinol after an acute attack of gout has passed, 1-2 weeks after an attack of gout has settled.

Self-management of fluid balance

Many patients are keen to help manage their fluid balance, though some patients and carers may require greater support from Heart Failure Specialist Nurse than others. Bathroom scales and a supply of diuretics are all that is needed!

- Determine the patient's target weight. For many patients with severe heart failure, this will be a weight that includes some excess fluid (i.e. leg oedema) below which significant renal impairment occurs. The patient should then
- Weigh themselves daily
- If overloaded limit fluid intake to around 1.5L daily.
- If weight increases by 2kg or more sustained over 2 or more days, the patient should take an extra daily diuretic (often an increased dose of loop diuretic or a dose of thiazide in addition to standard background loop diuretic therapy) until back to target
- If weight falls 2kg or more below target, the patient should omit half of that day's diuretic until back to target
- If weight changes by more than 5kg from target, the patient should seek help.

b. Digoxin

In selected patients with severe systolic dysfunction, digoxin may improve symptoms and function. It is particularly effective in patients with atrial fibrillation as it helps control ventricular rate, and it may be helpful in patients in sinus rhythm. It is often worth a therapeutic trial, but note that toxic effects (such as nausea) are more likely to be seen at lower doses when renal function is impaired. Avoid hypokalaemia in patients taking digoxin as it will precipitate toxicity at even low digoxin doses.

c. Nitro-vasodilators

Nitrates have little role in treating congestion as nitrate tolerance develops very rapidly and they are poorly absorbed after oral administration. They can be helpful in patients with acute symptoms, such as in paroxysmal nocturnal dyspnoea (PND), when administered sub-lingually. In patients with acute pulmonary oedema, intravenous infusion of nitrate can be very helpful. 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.

d. Morphine

Morphine can be effective for pain, cough and dyspnoea in patients with HF. It should be prescribed regularly *and* as required, with the breakthrough dose of Oramorph being one sixth of the total 24 hour dose of morphine. A usual starting dose of Oramorph would be 1mg-2.5mg every 4 hours and prn, using 1mg to begin with if the patient is frail or alternatively low dose sustained release morphine (MST 5mg bd).

Common problems on initiating morphine are nausea and drowsiness, which both tend to resolve within a few days. The nausea may need short term treatment with haloperidol 0.5-1.5mg nocte. **All patients on morphine should be co-prescribed laxatives** (see Constipation section). If the patient is already on morphine for pain, a dose increase of 30-50% may help with dyspnoea.

Active metabolites of morphine and other opioid drugs accumulate in renal impairment. In these cases, an alternative opioid should be used, usually oxycodone 1mg-2.5mg. Contact the Palliative Care Team for advice if needed.

e. Positive inotropic drugs

Most positive inotropic agents have to be administered intravenously, so they can only be administered in an acute hospital. This may make this treatment unacceptable to some end stage HF patients if priority is for care is in a community setting. However, symptoms may be severe and intractable despite all the other best available medical therapy. In such situations a few hours of inotropic support may provide much needed symptomatic benefit. Inotropic drugs all appear to worsen prognosis. Only dobutamine can be given through a peripheral vein: the others should usually be given via central venous access. In end stage disease, there should be careful patient selection and a clear intended benefit with regular review.

General principles for the withdrawal of cardiac drugs in end stage heart failure

Polypharmacy is prevalent and burdensome in palliative care. The burden of dual administration versus the benefits should be considered for each individual. As each patient will be different, this information is designed to be a guide rather than an absolute rule about the order in which to consider reducing therapy.

Cholesterol lowering drugs (e.g. statins) can usually be the first to be discontinued because they have no symptom relieving properties. They have also been shown not to improve prognosis in patients with heart failure.

Anti-arrhythmic drugs including beta-blockers can also be considered for down titration at an early stage. Most anti-arrhythmics lower blood pressure and can contribute to fatigue. If symptomatic tachycardias are present, or a drug such as a beta-blocker is also helping angina symptoms, it may be best to continue. In some patients, amiodarone can control otherwise very symptomatic arrhythmias, such as atrial fibrillation or episodes of ventricular tachycardia.

Anti-anginals can be discontinued if the patient has no angina. Antihypertensive drugs are usually also inappropriate.

If possible continue with ACE-inhibitors/ angiotensin receptor blockers as they do provide some symptomatic relief. However, stop if symptomatic hypotension, cough or the quantity of medications taken is troublesome.

Diuretics should be continued as long as possible, including loop diuretics (available in liquid form), thiazides and spironolactone.

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). They have never been shown to improve prognosis in heart failure, and aspirin in particular is associated with

an increase in the risk of hospital admission in patients with HF. Aspirin also antagonises diuretics and contributes to diuretic resistance - it should usually be stopped.

- Warfarin is mainly used to reduce the longer-term stroke risk, particularly in patients with atrial fibrillation. The decision to stop warfarin requires more discussion. Some patients do not wish to carry on having repeated blood tests to monitor INR control. Low molecular weight heparin (low or full dose) can be an alternative. The novel anticoagulants have not been used in clinical trials in this scenario but are an alternative in patients at high risk of thrombo-embolic problems in whom warfarin is inappropriate.
- If a patient with advanced HF is bed-bound, then their risk of venous thrombosis and pulmonary embolus is extremely high. If this situation is due to a deterioration which is likely to be reversible, then such a patient should usually be offered prophylaxis with low molecular weight heparin.

1.21. Last Days of Life

A significant percentage of patients with HF will die suddenly, however many will deteriorate more slowly and it is possible to recognise the very end stage of disease and to plan care.

In the community, patients entering end stage disease should be included in the Quality & outcomes Framework (QOF) register for palliative care and discussed at the practice MDT meeting. The Gold Standards Framework was developed nationally to help with co-ordination and planning of care. Information, including recommendations for which patients should be considered (Box1), relating to the GSF can be found at <http://www.goldstandardsframework.org.uk/>. EPaCCS can be used to record and share the outcome of any advance care planning including the wishes and preferences of the patient for place of death.

Include on the GSF Supportive Care register if 2 or more of the following apply:

- CHF NYHA III or IV
- Thought to be in last year of life
- Repeated hospital admissions with symptoms of heart failure
- Patient has difficult physical/psychological symptoms despite optimal tolerated therapy

Patients, family members and carers should have contact numbers for nursing, medical and any other services required throughout the 24 hour period. It is often more difficult to diagnose the terminal phase of HF than cancer. Consider the following points:

- Try to establish consensus within the team about a patient's condition
- It is often difficult to accept that deterioration does not represent failure by the health care team
- HF patients with advanced disease and acute deterioration may have reversible causes for the decline and achieve surprising improvement with medication changes
- If the chances of recovery are uncertain, share this with the patient and/or family and establish their preferences regarding aims & place of future care

Management of the dying phase

In hospital, use the Medical and Nursing Care Plans for the Last Days and Hours of Life, and the Guidance to support these. Information can be found on the intranet at <http://nww.hdft.nhs.uk/trust-wide/palliative-and-end-of-life-care/care-in-the-last-days-and-hours-of-life/>.

In the community, refer to Care Plan on EPaCCS and <https://www.harrogateandruraldistrictccq.nhs.uk/data/uploads/commissioning/hdft-last-days-or-hours-of-life-symptom-management-guidance-general-8-11..pdf>

National guidance can be found at:

www.gov.uk/government/publications/liverpool-care-pathway-reviewresponse-to-recommendations

NICE Guidance (NG31) – Care of dying adults in the last days of life: <https://www.nice.org.uk/guidance/ng31>

Recognition of the dying phase can be difficult in HF patients because there can be an initial response to corrective treatment. Decisions should be led by a senior clinician and involve the multi-disciplinary team. However the following features indicate that the patient is likely to be in the last phase of illness:

- brittle fluid balance control with no identifiable reversible precipitant
- diuretic resistance; failure to respond within 2 -3 days of appropriate change in treatment
- sustained hypotension
- unable to tolerate ACEI/ARBs or beta blockers
- worsening renal dysfunction □ resistant hyponatraemia
- hypoalbuminaemia

Note: HF patients with advanced disease and acute deterioration may achieve surprising improvement with medication changes. If there is uncertainty regarding the stage of illness, share this with patient and/or family. The following guidance, or use of end of life documentation does not preclude other appropriate management, or change of direction if it becomes apparent that

the patient is no longer dying. Daily review by the medical and nursing team is important.

Management of the dying phase

Achieving symptom control for patients in the last few days of life is greatly enhanced by having appropriate drugs readily available for managing common symptoms. This often involves **anticipatory prescribing** of drugs and ensuring that key drugs such as midazolam, morphine, hyoscine butylbromide and levomepromazine (plus water for injection) are readily available.

Further information regarding anticipatory prescribing of drugs and initial doses, please refer to the guidance above.

- As the patient becomes weaker and has difficulty swallowing, non-essential medications should be discontinued. Medication essential for symptom benefit can be converted to subcutaneous administration including analgesics, anxiolytics and furosemide.
- If fluid overload has been a significant symptom, diuretics should be continued, unless the patient has a poor oral intake. In general all other cardiac medications can be withdrawn.
- **Furosemide** can be administered subcutaneously and can be useful when venous access is difficult or unwanted. The following considerations should be taken:
 - Furosemide can be given as stat doses or continuous infusion via syringe driver
 - Compatibilities with other drugs are not known and mixing furosemide with other medication such as morphine or anxiolytics is therefore not recommended.
 - The recommended diluent is sodium chloride, but this is dose dependent and it can be used undiluted.
 - Patients with nickel allergy should have a “soft-set” or paediatric cannula if continuous infusion is needed.
 - Care must be taken to inject in non-oedematous skin as absorption may be affected in the presence of oedema. The upper anterior chest wall is usually oedema-free even when there is gross peripheral oedema.
- Stop intravenous hydration as it may worsen fluid retention and there is no clear evidence that it helps symptom control. Discuss this with the patient and family.
- Routine blood tests and measurement of BP, pulse and temperature should be stopped.
- Cardio Pulmonary Resuscitation (CPR) status should be established, communicated with the patient and their family and clearly documented. Where an ICD is in situ, see section 1.18 for advice.

- Assessment of symptoms and adjustment of medications as appropriate should occur regularly, including mouth, bladder and bowel care.
- Psychological support of patients and carer is very important and sensitive communication is of paramount importance including clear discussion of the aim of care.
- The patient's spiritual care requirements should be assessed and addressed.

1.22. The five common symptoms in the last few days of life

These are:

- Pain
- Breathlessness
- Nausea/vomiting
- Agitation/restlessness
- Respiratory tract secretions

Always prescribe the following 4 SC PRN medications:

- **Opioid analgesic:** choice and dose depends on the patient and previous opioid use
 - 1/6th of 24 hour dose of any regular opioid max hourly
 - If not on a regular opioid, morphine 1mg-2.5mg max hourly
- **Anti-emetic:** choice depends on the patient and previous anti-emetic use
If not nauseated and not on a regular anti-emetic, levomepromazine 2.5-6.25mg max 4 hourly
- **Midazolam** 2-5mg max hourly
- **Hyoscine butylbromide** 10-20mg max hourly

See the guidance in section 1.21 for further information.

1.23. Referral to The Palliative Care Team

All patients with HF require a supportive/palliative care approach with the aim of maximising their quality of life. This requires shared decision making between the patients, their carers and healthcare professionals. In most cases, the professionals already caring for them will be able to continue providing care. These guidelines are designed to help them. However, if the professionals caring for a patient are not able

to manage a problem satisfactorily, then referral to The Palliative Care Team should be considered, bearing in mind the eligibility criteria:

- Patients in any setting who have active, progressive and advanced disease for whom the prognosis is limited **AND**
- Have one or more of the following unmet needs:
 - **Symptom management** e.g. complex pain – when symptoms are not responding to appropriate current interventions
 - **Psychological /spiritual support** - patients or family/carers who are struggling psychologically or emotionally and need more support than can be provided by their current professionals
 - **Social support** e.g. support for patients and carers who have had a recent bereavement or who have limited coping strategies
 - **Hospice assessment** - assessment for hospice care for specialist symptom control, active rehabilitation, care in the last days of life, or day therapy
 - **Supporting decision making re: future care** especially when management is unclear
 - **Staff support** in dealing with difficult situations or debriefing following a death.

NB: All referrals should be made with the consent of the consultant or GP with clinical responsibility for the patient and with consent of the patients

See <http://nww.hdft.nhs.uk/trust-wide/palliative-and-end-of-life-care/> for information about the Harrogate Palliative Care Team.

Patients with HF requiring specialist palliative care referral usually have one of more of the following problems:

- Recurrent hospital admissions for de-compensated HF despite optimal medical treatment.
- Difficult communication issues (such as coping with uncertainty, prognosis, and preferred place of death).
- Difficulties in determining future care planning.
- Complex physical or psychological symptoms despite optimal tolerated therapy.
- Practical support needed to allow dying at home or hospice.
- Carers with high risk of bereavement difficulties.

Referrals to the Harrogate Hospital and Community Palliative Care Team can be made by phoning 01423 553464, electronically via SystemOne, or via a paper referral form or letter. See <http://www.hdfn.nhs.uk/trust-wide/palliative-and-end-of-life-care/referral-form-and-criteria/> for further details.

2. CONSULTATION, APPROVAL AND RATIFICATION PROCESS

Guideline development

1. Original guidelines:

The following guidelines were originally developed by a group coordinated by the North and East Yorkshire and Northern Lincolnshire Cardiac Network. Informal consensus methodology was used, and to ensure that this did not result in the 'pooling of ignorance as well as wisdom' (Hurwitz 1998). After an initial scoping exercise, a core group, comprising professionals from around the network area met to revise and update the existing guidelines and modify them for local use.

Core group membership original guidelines (July 2008):

Prof Andrew Clark, Chair of Clinical Cardiology, Hull York Medical School
Margaret Argent, BHF Heart Failure Nurse Specialist, Hull PCT
Christine Merrick, BHF Heart Failure Nurse Specialist, East Riding of Yorkshire PCT
Prof Miriam Johnson Professor of Palliative Medicine, Hull York Medical School. Honorary Consultant in Palliative Medicine, St Catherine's Hospice, Scarborough
Janet Raw, BHF Heart Failure Specialist Nurse (Scarborough area), North Yorkshire and York PCT
Debbie Leggott, BHF Heart Failure Specialist Nurse (Bridlington area), North Yorkshire and York PCT
Steve Hyde, BHF Heart Failure Specialist Nurse (York area), North Yorkshire and York PCT
Dr Sarah Anderson, Medical Director, Consultant in Palliative Care, St Leonard's Hospice, York
Dr Karen Dunderdale, Cardiac Rehabilitation Nurse, Scunthorpe General Hospital
Dr Robert Bain, Consultant Cardiologist, Grimsby General Hospital
Dr Paul Purser, Lead GP, St Andrews Hospice, Grimsby
Cheryl Orr, Community Matron, North Lincolnshire PCT
Anita Parker, Heart Failure Specialist Nurse, Hull and East Yorkshire Hospital Trust
Lisa Needham, Programme Manager/ Pharmacy Lecturer Medicines Management in Primary Care Programme, Leeds University/Hull PCT
Carol Hargreaves, Service Improvement Lead, North and East Yorkshire and Northern Lincolnshire Cardiac and Stroke Network

This finally agreed version was then ratified by the Provider Services Governance Board for Hull Teaching PCT – this being the host PCT for the NEYNL Cardiac and Stroke Network and to then submitted to the Network Management Board for approval.

2. Revised guidelines March 2015

The guidelines have been further updated (March 2015) by Professors Clark and Johnson, and Dr Hannah Leahy, Consultant in Palliative Medicine, Hull & East Yorkshire NHS Hospitals Trust in consultation with a range of health care professionals in the region from primary care, palliative care, medicine, nursing and allied health care professionals (see below).

List of consultees:

Dr Emma Dawber, GP

Amanda Goode, Heart failure nurse practitioner/lecturer

Andrina Greenlaw on behalf of the Humber Community Macmillan Team

Janet Raw, BHF Heart Failure Specialist Nurse

Dr Helen Rhodes, GP

Fiona Shepherd, Heart Failure Nurse Specialist, CHCP Hull

Dr Kate Thomas, GP

Dr Lia Van der Plaats, Macmillan Specialty Doctor Palliative Care, CHCP Hull

Alison Walker, Cardiac Specialist Nurse

Mandy Walters, Heart Failure Nurse Hull & East Yorkshire Hospitals NHS Trust

The revised guidelines were approved by: Yorkshire and the Humber Cardiac Network Regional Cardiac Services Clinical Expert Group March 2016.

Acknowledgements:

Thanks go to Adele Graham, West Yorkshire Cardiac Network and Merseyside and Cheshire Specialist Care and Cardiac Clinical Networks for her help with the original guidelines.

Thanks also to the Yorkshire and the Humber Cardiac Network Regional Cardiac Services Clinical Expert Group for their support.

3. HDFT review March 2020

This document has been reviewed by Dr Viv Barros D'Sa, Consultant in Palliative Medicine, for use in Harrogate and Rural District Locality and updated with local policies and guidelines. Thanks to Dr Kath Lambert, Consultant in Palliative Medicine, and Dr Bogusia Oledzka, Consultant in Cardiology, for their advice.

3. DOCUMENT CONTROL

Palliative Care Team

4. DISSEMINATION AND IMPLEMENTATION

Staff bulletin

Palliative and End of Life Care pages of HDFT intranet

Palliative Care pages on HaRD CCG website

5. REFERENCE AND ASSOCIATED DOCUMENTS

Booth S, Wade R, Johnson MJ et al. The use of oxygen in the palliation of breathlessness. A report of the expert working group of the scientific committee of the Association of Palliative Medicine. Respiratory Medicine. 2004; 98: 66–77.

British Heart Foundation (2007) – Implantable cardioverter defibrillators in patients who are reaching the end of life. A discussion document for health professionals.

BNF no. 78 (March 2015).

Available via <https://www.medicinescomplete.com/about/publications.htm>

Clinical Knowledge Summaries. Available via <http://cks.nice.org>

Currow DC, McDonald C, Oaten S et al. Once-daily opioids for chronic dyspnea: a dose increment and pharmacovigilance study. J Pain Symptom Manage 2011; 42(3):388-399.

Deactivation of implantable cardioverter-defibrillators towards the end of life A guide for healthcare professionals from the Resuscitation Council (UK) the British Cardiovascular Society and the National Council for Palliative Care. Pub. March 2015

Decisions relating to cardiopulmonary resuscitation - Guidance from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing, (Oct 2014).

Ekstrom MP, Bornefalk-Hermansson A, Abernethy AP, Currow DC. Safety of benzodiazepines and opioids in very severe respiratory disease: national prospective study. BMJ 2014; 348:g445.

Gold Standards framework available via www.goldstandardsframework.nhs.uk and www.modern.nhs.uk/chd

Hurwitz B (1998) Clinical guidelines and the law. Negligence, discretion and judgement. Radcliffe Medical Press Ltd

Johnson MJ. Management of end-stage cardiac failure. Post Graduate Medical Journal. 2007; 83: 395-401

Johnson MJ, Hogg K, Beattie B. Series Editor: Watson M. Heart failure: from advanced disease to bereavement. End of Life Series. OUP. April 2012

Johnson M, Lehman R (Eds) (2006) – Heart Failure and Palliative Care – a team approach. Radcliffe Publishing Ltd, UK

Johnson MJ, McDonagh T, Harkness A, MacKay S, Dargie H. Morphine for breathlessness in chronic heart failure. *European Journal of Heart Failure*. 2002; 4: 753–756.

NICE Guidance (NG31) – Care of dying adults in the last days of life:
<https://www.nice.org.uk/guidance/ng31>

Oxberry SG, Johnson MJ. Review of the evidence for the management of dyspnoea in patients with chronic heart failure. *Current Opinion in Supportive and Palliative Care* 2008, 2:84–88

Schmelz, M. Handwerker, H.O. 2004. Neurophysiology. In Zylicz, Z. Twycross, R. Jones, E.A. Editors. *Pruritus in advanced disease*. Oxford University Press. P 1132.

Pyatt JR, Trenbath D, Chester M and Connelly DT. The simultaneous use of a biventricular implantable cardioverter defibrillator (ICD) and transcutaneous electrical nerve stimulation (TENS) unit: implications for device interaction *Europace* (2003) 5, 91–93 doi:10.1053/eupc.2002.0277

Seccareccia, D. Gebara, N. 2011. *Pruritus in palliative care. Getting up to scratch. Palliative Care Files*. Vol 57. September, page 1010-1013.

Simon ST, Higginson IJ, Booth S, Harding R, Bausewein C. Benzodiazepines for the relief of breathlessness in advanced malignant and non-malignant diseases in adults. *Cochrane Database Syst Rev* 2010;(1):CD007354.

World Health Organisation. *Cancer Pain Relief (2e)*. World Health Organisation, Geneva, 1996 p.74

Xander, C. Meerpohl, J.J. Galandi, D. Buroh, S. Schwarzer, G. Antes, G. Becker, G. 2013. *Pharmacological interventions for pruritus in adult palliative care patients (Review)* The Cochrane collaboration Library. Wiley.

York Teaching Hospital NHS Foundation Trust Protocol for the Administration of Subcutaneous Furosemide in the Community Setting PROTOCOL FOR THE ADMINISTRATION OF SUBCUTANEOUS FUROSEMIDE IN THE COMMUNITY SETTING – Scarborough, Whitby and Ryedale locality (2012).

Palliative Care Formulary 6

6. APPENDICES

Appendix 1: Consultation Summary

<p>Those listed opposite have been consulted and any comments/actions incorporated as appropriate.</p> <p>The author must ensure that relevant individuals/groups have been involved in consultation as required prior to this document being submitted for approval.</p>	<p>List Groups and/or Individuals Consulted</p>
	Dr Bogusia Oledzka, Consultant in Cardiology
	Dr Kath Lambert, Consultant in Palliative Medicine
	HDFT Area Prescribing Committee