West Yorkshire Cardiac Network

Symptom Management Guidelines for patients in the later stages of heart failure and criteria for referral to specialist palliative care

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Version 3

Contents

Introduction

The following guidelines have been prepared to help and support healthcare professionals to manage the care of heart failure (HF) patients who are entering the later stages of their condition. The guidelines aim to complement other Palliative Care guidance for chronic disease. The guidance also addresses differences in approach when compared to the standard cardiological treatment of patients with milder forms of HF or other cardiac diseases. The emphasis is on symptom management.

These guidelines are designed to be complementary to standard medical treatment and at each stage of their use it is important to consider whether adjustments to standard treatment are required. In the context of "referral to specialist palliative care", it is important to note that symptom management and palliative care are applicable to the treatment of all HF patients. However, the emphasis of these guidelines is for the care of people in the later (or terminal) stages of HF.

They should be used in conjunction with national and local guidelines for management of heart failure including NICE Guidance (2003) and the West Yorkshire Minimum Standards of Care for Heart Failure (2005). They should also be read in conjunction with local and national guidelines on general palliative care.

The guidelines have been developed with information from patients and carers via the specialists involved in developing these guidelines.

Heart Failure arises from a reduction in the heart's ability to pump blood around the body adequately under optimal cardiac loading conditions, especially during exercise and stress. Most cases of HF in the UK are secondary to cumulative injuries from coronary artery disease, hypertensive heart disease, myocarditis, cardiomyopathy and/or valvular diseases. HF is increasing in prevalence and rises steeply with age. Patients with heart failure often have a very poor quality of life as well as high mortality rates (from 10% to over 50% depending on severity).

True end-stage HF is reached when (i) the patient is chronically and severely symptomatic (NYHA IIIb or IV), (ii) no further conventional therapy is available that will provide any realistic prospects of improvement without incurring undue risks to the patient, and (iii) the prognosis is very poor (e.g. life expectancy of <1 year).

The prognosis of patients with advanced HF is often difficult to determine for three reasons:

i Diagnostic uncertainty. There is no simple method for measuring organ function accurately in routine clinical practice;

ii The trajectory of deterioration in HF follows a fluctuating course. The many factors causing exacerbation of HF can often improve if the correct therapies are instituted in time;

iii A proportion of HF patients succumb because of sudden cardiac death (SCD). This is generally unpredictable; the majority of patients with HF will die from progressive cardiac pump dysfunction.

The uncertainties about prognosis need to be conveyed and discussed openly with the patient and their family/carers. Most importantly, the certainty with which the prognosis of HF is arrived at should not be over-stated, because the natural history of

HF, even for those confidently identified as "end-stage" may include some who spontaneously recover and improve, and others who die prematurely through SCD.

As HF is the result of cumulative disorders of components parts of the cardiac pump, and because of the complexities involved and diagnostic uncertainties, there is always a danger of diagnosing some patients as being in "end-stage" failure, when some remediable lesion(s) might be identified and corrected.
Current cardiological practice includes prophylactic therapies to prolong longevity that have been established and supported by grade A evidence. The consideration is often whether such therapies will enhance the quality of life of an individual patient. If in doubt, such cases should be referred to established HF specialists for further investigations and clarification.

Other important considerations for managing later stages of HF include:

- Optimum palliation of the symptoms of HF often depends on close monitoring and adjustments of medication on the clinicians' part, and adherence, especially with diuretics, on the patients' part.
- In the event of deterioration of symptoms, a treatable precipitant (eg non-compliance with medication, chest infection, anaemia, thyrotoxicosis, recent MI, arrhythmia) should be identified and managed first.
- Application of a holistic approach: considering physical, psychological, spiritual, cultural and social aspects.
- It is important to elicit particular concerns worrying or frightening the patient and to explore the meaning of a symptom. For example, when pain or breathlessness worsens, do they assume "I am getting worse?"
- Involve other members of the multidisciplinary team, including physiotherapist, occupational therapist, social worker, psychologist, carers, family members and spiritual support as appropriate.
- Try to negotiate the patient's preferred and most appropriate place of care, organising practical support as necessary
- Establish a plan for out of hours care: who to contact for advice, symptom management, patient's wishes concerning resuscitation, hospital admission.

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, Specialist Consultant in Palliative Care Medicine, Palliative Care Team).

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The group of health professionals involved in this piece of work are all highly skilled and experienced in their chosen fields, and our thanks go to them for their time and commitment to this project.

This document has also been circulated before completion to all West Yorkshire Consultant Cardiologists and Consultants in Palliative Care Medicine for their views, comments and approval.

Breathlessness

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

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 (eg chest infection, new atrial fibrillation, Pulmonary Embolus), consider one or more of the following palliative measures:

Non-Pharmacological Management

- Dyspnoea management, including breathing retraining, especially for hyperventilation syndrome
- Occupational therapy – lifestyle adjustments to minimise unnecessary exertion
- Psychological support – appreciating impact on lifestyle
- Anxiety management and education re management of panic attacks
- Relaxation
- Complementary therapies
- Fan

If patient reports daytime tiredness/insomnia and waking at night with gasping (or spouse/carer reports apnoea) consider sleep apnoea – This can be treated with non invasive ventilation using continuous positive airway pressure (CPAP) however, not all patients will tolerate this. Central sleep apnoea presents in 50% of later stage HF patients. Sleepiness/tiredness during the day or, waking at night and spouse reporting that they stop breathing, are signs of central sleep apnoea.

Pharmacological Management

- **Humidified oxygen starting at 24%. Do not exceed this concentration if co-existent COPD.** Nasal speculae are often more acceptable to patients than facemasks.

- **GTN Spray 1-2 puffs prn.** Contraindicated in severe aortic stenosis. May cause dizziness, especially if pre-existing hypotension.

- **Longer acting nitrates**. **Usually isosorbide mononitrate 30 – 120 mg MR od. GTN patches (10 – 20 mg)** for patients unable to swallow tablets. Important to provide at least 8 hours of nitrate-free period in each 24 hours day. IV nitrates allow closer titration of dose in acute cases.

- **Nebulised sodium chloride 0.9% +/- bronchodilators eg salbutamol 2.5 mg** or **terbutaline 2.5 mg prn to qds**

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 Palliative Care Formulary www.palliativedrugs.com

- if co-existing angina, ensure availability of GTN spray, as bronchodilators may precipitate angina in such patients

- **Low dose Morphine Sulphate Oral solution (eg Oramorph)– commencing at initial dose of 2.5 mg four hourly,** titrating up or down as needed and tolerated.

  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.

  - Immediate release (eg Oramorph, Sevredol) is more often effective for control of dyspnoea than sustained release (MST, MXL)
  - Morphine is excreted renally so if renal impairment/failure is present, should use low dose initially and reduce frequency to bd or tds depending on response, or seek Specialist Palliative Care advice for an alternative opioid that is tolerated better in renal failure.
  - Oxycodone is a strong opioid with pharmacological properties similar to morphine. It is a useful second line strong opioid for patients who have not tolerated morphine. Oral oxycodone is about 2 times more potent than oral morphine. Consult a dose conversion chart when starting oxycodone or ask advice from your local palliative care team or pharmacy (YCN Symptom management guidelines are available on www.ycn.nhs.uk, 2009)
  - Always use prophylactic laxatives when commencing strong opioids (see Review of Medication section Page 16)

- **Sublingual lorazepam 0.5 – 1 mg prn to max 4 mg per day –** rapid onset of action makes it particularly useful for panic attacks. **Diazepam 2 – 5 mg bd** is a longer acting agent. This effect may be useful but it can accumulate in hepatic impairment

- For patients who are sensitive to morphine, alternative opioids may be suitable and more advice regarding these can be obtained from the Specialist Palliative Care Team.

- If it is necessary for the patient to be alert and not sedated (e.g to discuss important domestic arrangements, the will, posthumous affairs, etc) a temporary relief of dyspnoea due to sever intractable HF may be achieved by using positive inotropic infusion titrated according to need **(e.g. dobutamine 5 – 40 microgram/kg/min)** administered intravenously.

Fatigue and Lethargy

This is one of the most common and difficult symptoms to treat. Common causes are:

- Low cardiac output or low BP: seek advice of Heart Failure Team or Specialist re 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 side effects of hypotension and fatigue are unacceptable.
- Hypovolaemia secondary to excessive diuretics dosages – adjust diuretic dose and frequency
- Anaemia: consider investigation/treatment by heart failure specialist/team
- Hyponatraemia/hypokalaemia - check U&Es
- Hypothyroidism – check TFT

Consider lifestyle adaptation, OT assessment re aids/appliances, coping strategies.

Seek advice from Cardiologist/Heart Failure specialist team if in doubt as to cause.

Peripheral Oedema

Peripheral oedema in HF is secondary to right heart congestion. Complications include leg ulceration, bedsores, stasis eczema, cellulitis. Peripheral oedema ranges from very mild, dependent ankle oedema occurring only in the evenings, to very severe associated with ascites and scrotal congestion. 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 are common in these patients and can be managed by the district nursing team who can seek further advice from a tissue viability nurse specialist if required. However, persistent and painful cases, especially those complicated by infected ulcerations, may need treatment with antibiotics for a prolonged period until resolution. It is worth remembering that low grade infections can worsen the severity of HF.

- Consider Aqueous cream + 0.5% menthol to reduce itch. Certain brands of medication with this combination may be documented on GP prescribing lists as unlicensed therefore it is suggested you liaise with the patients GP or your local pharmacist for further clarification.

- The district nursing team may review the need for further equipment at home, for example pressure relieving mattress, profiling bed etc and refer to others such as occupational therapy if required.

Dry Mouth

May be due to oxygen therapy (ensure 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/chips
- Chewing gum (Sugar free may reduce risk of dental caries and oral thrush)
- Pineapple juice (sipping or sucking pieces)
- Orange or Satsuma segments
- Oral balance gel
- Saliva stimulating tablets

Cough

Productive Cough

Consider the usual causes of cough such as chest infection or worsening pulmonary oedema.

Non-Productive Cough

Cough due to ACE I can begin some time after commencement, therefore consider a trial of withdrawal of ACE inhibitors for at least 1 week even if patient has been taking it for some time. If BP is high, consider replacing with Angiotension Receptor Blockers (eg "Sartan"). If BP is low, simply try withdrawing ACE I. It may be necessary to involve the healthcare professional managing the patient's HF treatment if this is considered.

If cough continues, consider the following:

- If difficulty in expectoration – **Nebulised Sodium Chloride 0.9% PRN. Usual dosage 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 – 10 mls PRN to qds** (please note that approximately 8-10% of the Caucasian population cannot metabolise codeine to morphine, therefore it is no different from simple linctus in these people)
  - **Low dose Oramorph** (starting dose **2.5 mg every 4 hours as tolerated**) **PRN**. May also help with SOB and pain.
    Always consider use of prophylactic laxatives when commencing strong opioids (see constipation and Review of Medication section Page 16)

For alternative options if the above are not effective, access Specialist Advice (Cardiology, Palliative Care).

Pain

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

- Angina and hepatic pain (the latter caused by congestion and also provoked by exertion) are both common in HF and both respond to oral nitrates.

- Musculoskeletal pain (arthritis) is also common in HF patients. Use of a standard analgesic ladder is appropriate for this pain. Paracetamol alone is often effective. **Systemic NSAIDS/Cox 2 inhibitors should be avoided if at all possible as they worsen HF**; topical agents are safer (although they are absorbed if used in large quantities), and may be very effective. (For opioids See Review of Medication section Page 16)

- Gout is also common and often due to diuretic treatment. For an acute attack, **Colchicine** is the treatment of choice. To reduce the likelihood of further episodes, consider whether diuretic dose can be reduced and treat with Allopurinol (using lower doses in those with renal impairment).

If required, further information on Pain is available within the Pain Management section of the Yorkshire Cancer Network Guide to Symptom Management in Palliative Care (Version 3).

(July 08 Addition) NB Patients with end stage heart failure are susceptible to impaired renal function which leads to accumulation of active metabolites of opioid drugs. Buprenorphine alfentanil and fentanyl are the safest drugs to use in these patients. Contact your palliative care team for advice in such cases.

Nausea and Vomiting

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

- Consider side effects of medication as causes for nausea and vomiting especially if worsening renal or hepatic function.
- If constant nausea, renal impairment or renal failure **haloperidol 1.5 – 3 mg orally/sc nocte.**
- If related to meals, early satiety, vomiting of undigested food, hepatomegaly:
  Metoclopramide 10 mg po/sc tds OR
  Domperidone 10 mg po tds OR
  Low dose levomepromazine 6.25 mg nocte – (tablet may allow 6mg) may also have anxiolytic effect

If the patient is nauseated most of the time, is vomiting, or considered to have gastric stasis, consider non oral routes of administration, including subcutaneous, as oral anti-emetics may not be adequately absorbed.

NB - Severe HF can result in poorer absorption of drugs (thought to be due to gut oedema).

Avoid cyclizine as this may worsen heart failure

If required, further information on Nausea and Vomiting is available within the Nausea and Vomiting section of the Yorkshire Cancer Network Guide to Symptom Management in Palliative Care (Version 3).

Weight Loss

Patients with HF may have a poor appetite and lose significant amounts of weight. Poor appetite is exacerbated by breathlessness, fatigue, oedema, drug reactions, renal impairment and depression.

The combination of reduced nutritional intake and increased requirements place the patient with HF at risk of malnutrition.
An unintentional weight loss of 10 per cent in 3-6 months is indicative of malnutrition.

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

- Dietary messages can be confusing in this client group as patients may be following previous 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 non-oedematous weight may have an improved sense of well being and improved body image.
- There may be family expectations relating to food intake and this can make mealtimes stressful. In general, give permission for the patient to eat as much or as little of whatever they want. Encourage small frequent meals and snacks. This may help with nausea and bloating.
- Many patients may be following a no added salt diet, based on previously given dietary advice. If they are struggling with the palatability of a no added salt diet, it can be relaxed at this stage to improve intake.
- Patients may need assistance with shopping and cooking.
- Use of oral nutritional supplements may be appropriate and of benefit to some patients. Refer to a Dietitian for advice regarding the use of prescribable dietary supplements.

Vitamin supplementation, this is generally not used. There is no evidence to support any benefit.

Constipation

- May be triggered by reduced intake of fluids and food, diuretics, verapamil, immobility, weak or strong opioids (See Review of Medication section Page 16). **NB - Prescribe laxatives routinely when commencing opioids. If stopping verapamil discuss with cardiologist or heart failure nurse specialist first.**

- If patient can manage the volume, **Idrolax** is preferable to **Movicol** (the latter has a higher Na+ content).

- Co-danthramer Strong Suspension (75/1000) 5ml daily or bd – patients can titrate according to their need. Patients should be advised that their urine will turn a reddish colour. Should be avoided in patients with urinary or faecal incontinence as it may cause a rash.

  Co-danthramer works as a combination of faecal softening and motility stimulant action. Similar results can be achieved with senna as the motility stimulant **(starting dose 2 tablets nocte)** and docusate **(starting dose 100mg bd).** Lactulose is commonly prescribed as a softener, **but causes abdominal bloating in many patients and is therefore not the softener of choice in palliative care patients. Lactulose also has a high sugar content, which could be problematic for diabetic patients but less important for palliative care patients.**

If required, further information on Constipation is available within the Constipation section of the Yorkshire Cancer Network Guide to Symptom Management in Palliative Care (Version 3).

Anxiety and Depression

At least one third of HF patients suffer from depression. Exploration of the underlying issues is essential and may be all that is required. Some patients require specific drug treatment and the following are considered safe:

Antidepressants. Avoid tricyclic antidepressants in view of cardiotoxic side-effects.

- **Citalopram 20 mg** daily would be appropriate.
- **Sertraline 50 mg** is a suitable first line agent for anxiety **with** depression.
- **Mirtazepine 15 – 30 mg nocte** is an alternative, especially if nausea or poor appetite are associated problems.
  NB - less sedating at 30 mg than at 15 mg (refer to palliative care formulary if required)

Anxiolytics

- **Lorazepam 0.5 – 1 mg s/l prn to a max of 4 mg per 24 hours (individual doses).** The s/l preparation is especially useful for panic attacks
- **Diazepam 2 – 5 mg po nocte.** Longer acting than Lorazepam – effective for more persistent anxiety.
- **Fluoxetine 20–60mg daily (20-40mg daily in the elderly)**
- **Citalopram 10mg** would be appropriate for Panic Attacks

Insomnia

Establish contributory factors such as anxiety, 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 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 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). Use of GTN spray can give immediate, short term relief (avoid use in severe aortic stenosis).
- Relaxation and anxiety management

In addition, the following pharmacological management is available:

Night Sedation: **Temazapam 10 – 20 mg nocte**
Lorazepam 0.5 – 1 mg nocte
Zopiclone 3.75 or 7.5 mg nocte

If insomnia is associated with nausea, or if benzodiazapines do not work, consider haloperidol, chlormethiazole or levomepromazine.

If terminal stage, or if other treatments fail, consider opioids (see Review of Medication section Page 16) for night sedation.

Review of Medication

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 fall into two categories:

a. Those used for prophylactic therapy to improve HF prognosis
b. Those providing symptom relief ± improvement in functional capacity

The principles of continuation or withdrawal of medication for late-stage HF patients therefore consist of 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 to improve symptoms or function (e.g. duiretics, digoxin, vasodilators) should be continued, but the dosages should be monitored, reviewed regularly and adjusted accordingly.
3. Always use the lowest doses of drugs necessary to produce the desired symptomatic benefits, discarding the concept of targeting for "trial-proven doses".
4. The frequency and doses of drugs should be given to cover sufficient durations. Inadequate regime resulting in frequent break-through symptoms can interrupt restful sleep and be quite 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.
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 vasodilation can lower BP as to induce 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 of inappropriate 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, e.g. some individuals' aversions to PR or PV routes.
    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.

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.

Diuretics

Despite the lack of large-scale randomised controlled trials, diuretics are still accepted as the first line therapy for congestive HF.

Diuretics are necessary because a natural compensatory mechanism in HF is to trigger retention of fluid. 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 = output. Because either side of the equation can change independently, it is important to remember that diuretic dosages may require 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. 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 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) may be better tolerated and improve compliance.

The use of combination diuretics require special mention:

- Loop diuretics and metolazone combination is particularly potent and may be used sparingly to "kick-start" diuresis, especially when IV administration is not an option. It is also particularly liable to upset electrolyte balance, especially hyponatraemia which is the most harmful and difficult to treat.
- Loop and thiazide diuretics combination is similar to the above but may not be as powerful.

- Loop or thiazide diuretics have propensity to induce hypokalaemia and hypomagnesaemia. The combined use of K+- sparing diuretics is more effective than K+ supplementation.

In diuretic resistance late-stage HF with severe symptomatic congestion, it may be necessary to resort to temporary inotropic therapy or even dialysis/filtration to relieve the distressing congestive symptoms. Once the oedema has resolved, provided there is still adequate renal function, the patient may become responsive to and able to be maintained with oral diuretic therapy again. Appropriateness of hospital admission for this treatment will need to be discussed with the patient and the cardiologist

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.

Vasodilators

Vasodilators such as nitrates are helpful in relieving the symptoms of venous congestions, complementing the effects of diuretics. They should be continued in patients experiencing angina. NB Symptoms may improve with a low dose vasodilator therapy but paradoxically worsen with larger doses.

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 2.5 - 5 mg every 4 hours and prn, using 2.5 mg if the patient is frail.

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 1.5 – 3 mg nocte**. All patients on morphine need laxatives (see Constipation section, page 13), which should be co-prescribed. 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, the frequency of administration should be reduced, ie prescribe Oramorph either tds or even bd (and prn). Avoid slow release preparations. **(July 08 Addition)** If these are felt necessary, buprenorphine, fentanyl and alfentanil are the safest drugs to use in renal failure. Refer to your palliative care team for advice.

If any problems occur with morphine, alternative opioids are available – discuss with your local palliative care team.

Inotropes

Most positive inotropic agents have to be administered intravenously. As such, there is usually no place for inotropic therapy for palliative care stage HF. 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.

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 (eg statins) can usually be the first to be discontinued because they have no symptom relieving properties.

Anti-arrhythmic drugs including beta-blockers can also be considered for discontinuation 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 betablocker is also helping angina symptoms, it may be best to continue. Digoxin does provide some symptom relief so this therapy may be continued, unless swallowing medication is a problem or side effects such as nausea develop.

Anti-anginals can be discontinued if the patient is asymptomatic.

If possible continue with ACE-inhibitors/Angiotension 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 (can have 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). If symptoms are stable and the prognosis is poor from the HF, these need not be continued. Anticoagulants (Warfarin) are mainly given to lower the longer-term stroke risk. The decision to stop Warfarin requires more discussion. Some patients do not wish to carry on having repeated blood tests to monitor INR control. Clexane (low or full dose) can be an alternative.

Withdrawal of Devices or ICDs

What is an ICD?

An ICD is an implantable cardioverter defibrillator. It is a device which is able to give the heart electrical shocks. Defibrillators are increasingly commonplace in the management of HF especially those combined with cardiac resynchronisation pacing (CRT). These devices are a more complex form of a permanent pacemaker, able to deliver an electric shock to help lower the chance of sudden cardiac death (SCD) from a ventricular dysrrhythmia.

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 a perceived 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).

Principles:

- Eventual withdrawal of ICD care should be discussed prior to initial implant, in all ICD recipients.
- 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 patients wishes should be respected if they wish to continue active resuscitation attempts.
- ICD patients should be encouraged to express their concerns especially in relation to their mode of death and shocks.

Where the focus of care is more terminal, 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 tachyarrhythmia therapies turned off.

For further information the British Heart Foundation and Arrhythmia Alliance have downloadable files on ICD's and deactivation of ICD's in the dying patient (link available in references section)

When anti-arrhythmic medical therapy is being withdrawn patients should be aware that device activation is more likely and they may consider switching off shocks.

Deactivation of the device in the community setting is problematic. It should be considered and discussed at the same time as do not resuscitate decisions are made; and ideally be discussed if a patient is being discharged from hospital to palliative community care. It is incompatible that a patient should have an active ICD but otherwise not be for resuscitation.

There should be liaison with defibrillator clinic and specialist nursing staff along with the supervising electrophysiologist/device physician when deactivation is being considered.

Magnets are only of value in temporarily deactivating defibrillators and should only be used by emergency personnel.

When a patient dies with an active ICD the follow up defibrillator 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.

Financial Benefits

Patients with later stages of HF are eligible for:

- Attendance Allowance – if over 65 years. Disability Living Allowance - if under 65. An application pack is required if the prognosis is thought likely to be less than six months (They are available from social workers and some palliative care teams). The GP or hospital doctor should sign the DS1500 form within the pack. This is known as applying under the "special rules" and the application will be treated as a priority. If patients need help to complete these forms or further benefits advice, local help is available from one stop shops, citizen's advice bureaux, Age Concern, Welfare rights etc.

- Free Prescriptions

Terminal Heart Failure – Last Few Days of Life

In primary care it is good practice to work within the Gold Standards Framework. Late stage HF patients should be identified on the supportive register and discussed at the practice meetings on a regular basis. Discussions around preferred place of care, management plans and support available are extremely beneficial for all concerned. Patients, family members and carers should have contact numbers for nursing, medical and any other services required throughout the 24 hour period. It is important to communicate this information and complete a hand-over form. Information relating to the Gold Standards Framework can be found at www.goldstandardframework.nhs.uk.

It is often more difficult to diagnose the terminal phase of HF than cancer. A high proportion of patients with HF (up to 40-50% in some studies) will experience sudden death. However, others deteriorate more slowly and the Gold Standards Framework can be helpful in planning their care. 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.

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

- Increasing frequency of hospital admissions (despite optimum tolerated conventional drugs) with no identifiable cause or no identifiable reversible cause
- Worsening renal function
- Failure to respond within two to three days to appropriate change in diuretic or vasodilator drugs
- Sustained hypotension
- Increasing fatigue
- Becoming largely confined to bed

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 prn doses available.

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 Palliative Care Formulary www.palliativedrugs.com

- Discontinue inappropriate procedures such as venepuncture and checking of temperature, BP etc.

- 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.

Symptom control in the last few days of life

Liverpool Integrated Care Pathway (LCP)

The LCP is an integrated care pathway that is used at the bedside to drive up sustained quality of the dying in the last hours and days of life.

It is a means to transfer the best quality for care of the dying from the hospice movement into other clinical areas, so that wherever the person is dying there can be an equitable model of care (http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/, 2009)

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.**

COMMON SYMPTOMS

Breathlessness

OPIOID NAÏVE: Morphine/Diamorphine 2.5 – 5mg subcutaneous 4-6 hourly prn as a starting dose. If effective consider adding an appropriate dose to a syringe driver to deliver over 24 hours.

PATIENTS ON OPIOIDS: In patients already on oral morphine or another opioid it is advisable to set up a syringe driver with an appropriate amount of opioid. (For morphine this will be half the total daily oral morphine dose; for example someone on 5mg Oramorph qds would require 10mg morphine sulphate over 24 hours in a syringe driver).

Anxiety often accompanies breathlessness, consider **midazolam 2.5 - 5mg sc prn** to manage this (5mg unless very frail and cachextic). It can be repeated 2-4 hourly if effective, or given via a syringe driver over 24 hours, dose depends on requirement in

the previous 24 hours. **10mg/24 hours is a common starting dose.** It can be put in the same syringe driver as the opioid.

Pain

OPIOID NAÏVE: Morphine/Diamorphine 2.5 – 5mg subcutaneous 4–6 hourly prn as a starting dose. Titrate dose according to response. If effective, and requiring frequent doses, consider adding an appropriate dose to a syringe driver to deliver over 24 hours.

PATIENTS ON OPIOIDS: In patients already on oral morphine or another opioid it is advisable to set up a syringe driver with an appropriate amount of opioid. (For morphine this will be half the total daily oral morphine dose for example someone on 5mg Oramorph qds would require 10mg morphine sulphate over 24 hours in a syringe driver).

Agitation, terminal restlessness

Exclude manageable precipitating factors such as urinary retention, faecal impaction, pain, uncomfortable position in bed. Use an anxiolytic such as **midazolam 2.5 – 5mg** subcutaneous 2–4 hourly (5mg unless very frail and cachexic) . If repeated doses are required, consider adding midazolam to a 24 hour syringe driver, the dose will depend on what dose was required to settle the patient.

Haloperidol is indicated for the management of delirium. Assess response to a stat dose of 1.5mg o/subcut in the elderly, or 3-5mg in younger patients (PCF3). Thereafter,**1-3mg** by mouth up to every 8 hours. Haloperidol has little sedative effect, and can be given as a subcutaneous infusion dose of **5-15mg** over 24 hours (BNF, 2010).

Nausea and vomiting

Haloperidol 3 – 5mg over 24 hours via syringe driver.
Levomepromazine 6.25mg – 12.5mg over 24 hours via a syringe driver or as a subcutaneous stat dose. (Note that it is more sedating than Haloperidol)

Retained secretions in upper respiratory tract

Changing position of the patient may be helpful to allow drainage of retained secretions. Early management with drugs may prevent further secretions collecting. **Hyoscine hydrobromide 400-600mcg** subcutaneous stat every 4-8 hours and if effective deliver via syringe driver at a dose of **0.6-2.0mg** over 24 hours (BNF, 2010)

Hyoscine butylbromide is a less sedating alternative to **Hyoscine hydrobromide** Start with **Hyoscine butylbromide 20mg sc stat, and 20 -60mg/24hours** by subcutaneous infusion dose (PCF3). Do not use in addition to hyoscine hydrobromide.

Important this dose of **Hyoscine butylbromide** must not be confused with the much lower dose of **Hyoscine hydrobromide** (BNF, 2010)

An alternative is **glycopyrronium 200mcg** stat subcutaneously every 4 hours or by subcutaneous infusion **0.6-1.2mg** over 24 hours via syringe driver (BNF, 2010).

If symptoms of retained secretions persist, reassess for signs of pulmonary oedema or reflux of gastric secretions, and seek specialist palliative care advice if necessary.

Patients vary in the amount of drug they may require to gain control of symptoms. It is important to review the patient regularly and consider whether drugs need to be continued or doses titrated down or up more often.

If you are unsure about appropriate doses or any other part of the patient's management, please contact your local specialist palliative care service. All services have 24 hour advice available.

Syringe drivers should be readily available, although different arrangements exist in different districts. If you are unsure of how to access them, please contact your local hospital or community palliative care team.

It is important to highlight that in addition to the above, the Liverpool Integrated Care Pathway for the dying has symptom control algorithms within it.

Referral to Specialist Palliative Care Teams

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 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, bearing in mind the eligibility criteria for the local services. People 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, particularly if considered by HF or cardiology specialists to have no prospect for improvement.
- Cases where there are difficult communication issues (such as coping with uncertainty, prognosis, preferred place of death).
- Cases where there are difficulties in determining future care planning.
- Complex physical or psychological symptoms despite optimal tolerated therapy.
- Social isolation.
- Practical support needed to allow dying at home.
- Carers with high risk of bereavement difficulties.

Of course each area may have developed their own criteria for referral to Palliative Care, the above is used as a guide and individual area guidance must first be applied.

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