



SWL Supportive and Palliative Care Group
and SWL Cardiac Network



Symptom Control Guidelines and key information in end-stage heart failure

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Specific Symptoms

Preface

This guidance is aimed at specialist and non-specialist health professionals who care for patients with end-stage heart failure. It was developed by members of the SWL Supportive and Palliative Care Group and SWL Cardiac Network. Neither the authors, SWL Supportive and Palliative Care Group nor SWL Cardiac Network take responsibility for the application of these recommendations. The ultimate responsibility lies with the health professionals who assess, manage and deliver care. If further advice is required please contact your local specialist palliative care team or cardiac specialist. Triggers for referral to specialist palliative care services are included as Appendix 1.

Introduction

- ❖ Symptom control for patients with end-stage heart failure should continue in conjunction with optimal heart failure treatment. This is the first step to achieving good symptom control. This may include diuretics, ACE inhibitors etc as long as these medications remain appropriate.
- ❖ The burden of chronic heart failure has physical, psychological, social and spiritual dimensions which need to be considered when planning symptom management.

Breathlessness

The management of breathlessness includes identifying possible causes other than heart failure such as pharmacological causes eg B-blockers, anaemia, fatigue and psychological causes including anxiety.

Non-pharmacological management

- ❖ Breathing retraining.
- ❖ lifestyle adjustments- educate the patient to adjust and conserve energy for activities which are important to them.
- ❖ Psychological support - appreciating impact on lifestyle.
- ❖ Enable patient to feel in control by reducing anxiety and panic.
- ❖ Relaxation and distraction techniques.
- ❖ Complementary therapies.
- ❖ Fan.
- ❖ Where appropriate planned exercise programmes e.g. breathlessness management groups.

Pharmacological management

Low dose oral morphine solution - commencing at initial dose of 2.5mg 4 hrly, dose may be increased if well tolerated.

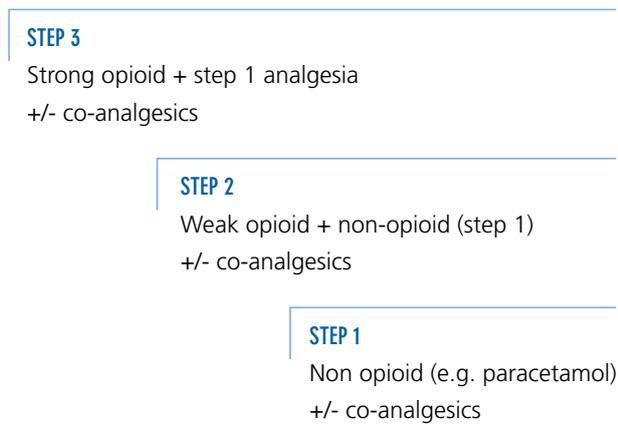
- ❖ Morphine is excreted renally. Seek advice if renal function poor or if there are signs of opioid toxicity.
- ❖ Co-prescribe regular laxatives when commencing regular strong opioids.
- ❖ **Sublingual lorazepam 0.5 - 1mg prn to max 4mg per day** - especially if elements of anxiety or panic. May cause sleepiness.
- ❖ Diazepam 2mg po - once a day if background anxiolytic required.
- ❖ Humidified oxygen if hypoxic - starting at 24% and continuing at this concentration if co-existent COPD. Consider use of nasal specs.
- ❖ GTN spray 1 - 2 puffs prn. May be effective in acute pulmonary oedema. Beware of hypotension. Contraindicated in severe aortic stenosis.

Pain

Studies have shown that up to 78% of patients with heart failure experience some degree of pain. Probably due to a combination of angina, liver capsule distension, lower limb oedema, inactivity and co-morbidity diseases, e.g. arthritis.

- ❖ When assessing the patient consider psychological, emotional and spiritual aspects that may be influencing the pain.

Figure 1: WHO Analgesic Ladder



For STEP 1

- ❖ Start treatment with paracetamol 1g every 4 hours REGULARLY. (Max daily dose 4g).
- ❖ If this is not adequate in 24 hours, stop and proceed to STEP 2.

For STEP 2

- ❖ Start treatment with a combined preparation of paracetamol with codeine or dihydrocodeine.
- ❖ If this is not adequate, stop and proceed to STEP 3.

For STEP 3

- ❖ For patients who are opioid naive commence **oral morphine solution 2.5mg up to 4 hourly**, titrate up as necessary.
- ❖ Caution should be exercised in patients who are elderly or in renal failure. Reduce dose / dose frequency in renal impairment.
- ❖ For further advice regarding alternative opioids contact the Specialist Palliative Care Team
- ❖ Remember to prescribe regular laxatives when using regular opioids.

- ❖ A multi-disciplinary approach to pain control is often necessary e.g. Physiotherapists, Occupational Therapists, Social Workers, Chaplaincy Teams etc.
- ❖ Remember to consider other causes and pathologies in addition to heart failure.
- ❖ Follow the WHO Analgesic ladder (figure 1).



- ❖ Non-steroidal anti-inflammatory agents including COX II inhibitors can worsen heart failure and renal function so should be best avoided. Should only be considered in a terminal care situation.

NB: for more information on pain control and the use of co-analgesic therapy please see the Palliative Care Guidance (Watson, Lucas and Hoy, 2006).

Cough

Cough is often attributed to ACE inhibitors. However, patients should be assessed for other causes before they are discontinued, especially in patients who have been taking them long-term. Prolonged bouts of coughing are exhausting and frightening.

Management

This will depend on the cause of the cough. It is important to distinguish if it is a productive, wet or dry cough.

- ❖ If related to difficulty expectorating and patient is still able to cough effectively - **nebulised Normal Saline 0.9% - 2.5mls PRN** may help to loosen tenacious mucus and aid expectoration.

- ❖ Cough suppressants - (for dry irritable cough)
Simple linctus 5 - 10 mls PRN to qds
Codeine linctus 5 - 10mls PRN to qds
Low dose oral morphine solution - starting dose **2mg PRN.**
Low dose methadone at night - starting dose **4mg nocte**

Nausea and Vomiting

Nausea and vomiting are symptoms that cause patients and family members much distress. Patients may have multiple causes of nausea and vomiting. Therefore, it is important to identify the possible causes, treat reversible causes (e.g. constipation, infection, anxiety etc.) or commence appropriate therapy.

- ❖ Consider current drug cause for nausea and vomiting and review.
- ❖ If nausea predominantly caused by renal impairment or drug induced: **haloperidol 1.5mg orally/sc nocte**
- ❖ If nausea or vomiting related to eating, gastric stasis, early satiety or **hepatomegaly** consider
Metoclopramide 10mg po/sc tds
Domperidone 10mg po tds

N.B. AVOID CYCLIZINE AS THIS MAY WORSEN HEART FAILURE.

Constipation

Complications of constipation include pain, bowel obstruction, overflow diarrhoea and urinary retention. All these symptoms can cause much concern and distress for patients and family members and therefore should be prevented where possible. Patients with heart failure can become constipated due to poor mobility, poor fluid or dietary intake or their drugs e.g diuretics and opioids.

- ❖ The choice of laxative will depend on the cause. Patients may need:
 - a stool softener – **e.g. docusate sodium 100 - 200mg o.d. – t.d.s.**
 - a stimulant laxative eg **senna 2 tablets or 10mls nocte**
 - a combination laxative **e.g. co-danthramer 1-2 capsules or 5-10mls nocte.** (licensed for use by terminally ill patients). Avoid if incontinent of urine and/or faeces as the danthron in co-danthramer may cause skin excoriation.

Anxiety and Depression

It is normal for a patient to experience anxiety when living with a life limiting illness. It is common for a number of reasons including the fear of uncontrolled symptoms and being left alone to die. Anxiety becomes a problem when its duration and severity exceeds normal expectations. It is important to explore underlying issues and deal with these if possible, by means of a holistic approach involving all appropriate members of the multidisciplinary team.

It is important to provide time for patients to express their worries and concerns. Relaxation techniques, various complementary therapies if available and drug therapies may help. Anxiety can also be a feature of underlying depression. Depression is a major symptom for patient with heart failure and is associated with increased readmission rates and an increased mortality.

Drug therapies may be helpful to break the anxiety cycle and restore sleep:

Anxiolytics

Lorazepam 0.5-1mg sublingually for panic attacks
Diazepam 2mg po once a day - for background anxiety

Night sedation

Lorazepam 0.5 - 1mg nocte
Or Temazepam 10 - 20mg nocte

Antidepressants.

Sertraline 50mg o.d.
Or Citalopram 10 - 20mg o.d.
Or Mirtazapine 15 - 30 mg nocte

N.B. AVOID TRICYCLIC ANTIDEPRESSANTS IN VIEW OF CARDIOTOXIC SIDE-EFFECTS

Peripheral Oedema

Patients with heart failure may present with peripheral oedema in the arms, legs and genitalia.

Management strategies

- ❖ Adjustment to diuretics (Appendix 2)

- ❖ Education on good skin care is required to prevent dryness, cracking and infection.
E.g. Dry skin – **aqueous cream or simple moisturiser**
Dry and itchy skin – **aqueous cream + 0.5% menthol.**
- ❖ Compression bandaging may help. This will require input from DNs or lymphoedema nurse specialists if accessible.
- ❖ Scrotal support for scrotal oedema may improve comfort.
- ❖ An OT, Physiotherapy or Social Work assessment may be required to assist patients and families to adjust to changes to independence.

Dry Mouth

A dry, uncomfortable mouth can impact greatly the patients' quality of life. It is important to assess the mouth and consider underlying causes e.g. medication, poor oral hygiene, oral candida and oxygen therapy.

Management strategies

- ❖ Sipping semi-frozen drinks
- ❖ Sucking ice chips
- ❖ Chewing gum (sugar free)
- ❖ Pineapple (fresh or tinned) to chew
- ❖ Oral balance gel or saliva substitute sprays.
- ❖ Moisturising cream or soft paraffin to the lips
- ❖ Soak dentures overnight

Anorexia, Cachexia and Nutrition

Patients with heart failure may have poor appetite and lose significant amounts of weight. The focus of earlier dietary advice may need to be revised on the basis of reassessment.

- ❖ Fat-soluble vitamins may be appropriate.
- ❖ For cachectic patients a high calorie, high protein diet with no added salt may be beneficial.

- ❖ Patients may develop low cholesterol levels and in these circumstances statin medication should be discontinued.
- ❖ Small meals, attractively presented.

Terminal Heart failure - the last few days of life

A high proportion of patients with confirmed heart failure, up to 40 - 50% in some studies will experience sudden cardiac death. Others will deteriorate more slowly.

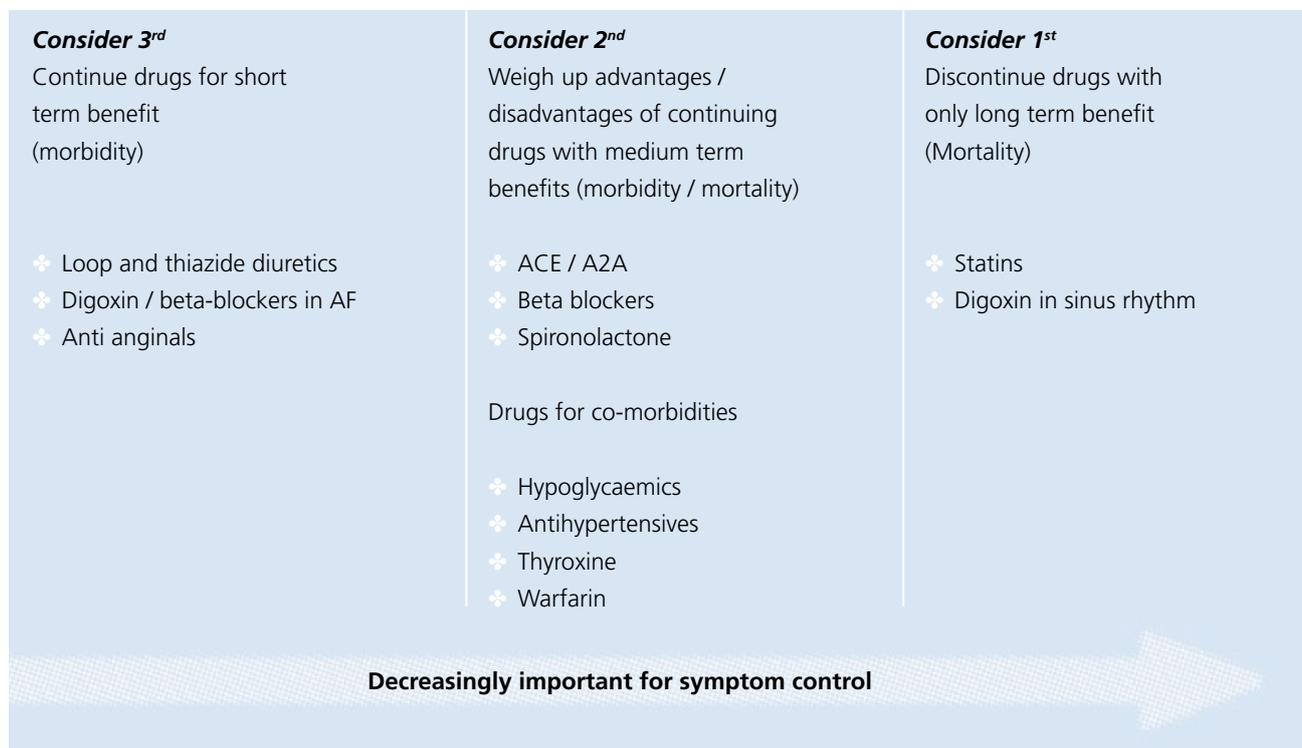
- ❖ Need agreement within the MD team that the patient is dying.
- ❖ Often difficult accepting that deterioration does not represent failure to the health care team.
- ❖ Important to recognise patients who appear to be approaching terminal phase of their illness. It is more difficult to diagnose dying in heart failure than in many terminal cancer patients and to define when they are in a palliative phase.
- ❖ In heart failure, patients may achieve improvement with medication, may have reversible precipitant.

If recovery uncertain, this needs to be shared with patient and family and explore patients wishes in terms of options for care and place of care.

The subgroup to identify is those patients with:

- Previous admissions with worsening heart failure.
- No identifiable reversible precipitant.
- Receiving optimum tolerated conventional drugs.
- Worsening renal function.
- Failure to respond within 2 - 3 days to appropriate change in diuretic or vasodilator drugs.
- Sustained hypotension.

Figure 2: Heart Failure Discontinuation Strategy



(Used with permission of Dr Louise Gibbs)

- ❖ As patient becomes weaker and has difficulty swallowing, need to discontinue non-essential medications, but continue those which will provide symptomatic benefit (figure 2).
- ❖ Such essential medications as analgesia, antiemetics, anxiolytics, opioids and diuretics can be converted to subcutaneous doses if appropriate and given continuously over 24 hours via syringe driver with PRN doses available.
- ❖ Should discontinue such inappropriate invasive procedures as venepuncture and checking of temp, BP etc. Need to establish inappropriateness of CPR, and may also need to discuss with patient and family discontinuing of intravenous hydration.
- ❖ Need regular assessment of symptoms and adjustment of medications if symptoms not adequately controlled.
- ❖ Psychological support of patient and family very important. Good clear but sensitive communication of paramount importance.
- ❖ Spiritual care according to patient's cultural and religious beliefs important.

- ❖ If specialist advice is required please contact your local specialist palliative care team or cardiac specialist.

Implantable Cardioverter Defibrillator (ICD)

- ❖ If the patient has an implantable cardioverter defibrillator (ICD) it is important to consider and where appropriate discuss with patient and family when would be an appropriate time to switch this off by a technician. In an emergency situation an ICD can be deactivated by applying a large magnet to the area of the chest where the ICD has been inserted.

Useful resources

- ❖ British Heart Foundation (2007) discussion document on 'Implantable cardioverter defibrillators in patients who are reaching the end of life' (www.bhf.co.uk).
- ❖ www.heartrhythmcharity.org.uk/html/icd_deactivation.html.

Breathlessness

Diamorphine at initial dose of 1 - 2.5mg sc 4 to 6 hourly + PRN dose if not on oral morphine.

If patient is on oral morphine or other strong opioid, seek advice of Palliative Care Team regarding appropriate starting dose of diamorphine. (To calculate dose of subcutaneous diamorphine divide the dose of oral morphine by 3).

If effective, consider commencing syringe driver with diamorphine, dose dependent on the amount of oral morphine and sc diamorphine required in previous 24 hours.

In moderate to severe renal failure there are alternative opioids available, which are better tolerated. Please seek advice of Palliative Care Team.

If patient is breathless and anxious, consider lorazepam 0.5mg sublingually. If unable to tolerate, consider midazolam 2.5mg sc stat. If effective, this can be repeated or midazolam given in syringe driver with diamorphine if appropriate, the dose dependent on requirements in the previous 24 hours.

Pain

Diamorphine 1 - 2.5mg sc 4 to 6 hourly if the patient is not on oral morphine, and titrate according to response and pain.

If patient is already on oral morphine or other strong opioid, consult Palliative Care Team for advice on starting dose of diamorphine.

If patient requiring frequent doses, consider subcutaneous infusion via syringe driver with dose of diamorphine dependent on requirements in previous 24 hours.

Agitation, terminal restlessness, delirium

Exclude precipitating factors such as urinary retention, faecal impaction, pain, uncomfortable position in bed, and address these appropriately.

If patient agitated or restless consider midazolam 2.5 - 5mg sc PRN.

If repeated doses required, consider commencing syringe driver with dose dependent on requirements of previous 24 hours.

If patient delirious consider haloperidol 1.5mg sc PRN. If repeated doses required consider commencing a syringe driver with haloperidol 3-5mg in 24 hours.

Diamorphine alone is not appropriate.

Nausea and vomiting

Haloperidol 1.5 – 3mg over 24 hours via syringe driver.

Levomopromazine 3.125 – 6.25mg over 24 hours via syringe driver.

Retained secretions in upper respiratory tract

May be of major concern to the family, but not distressing for patient. Patient too weak to expectorate secretions. Changing position of bed or raising head of bed may help, and once patient is semi-conscious nursing in coma position will be most useful for drainage of retained secretions.

If secretions persist consider glycopyrronium 0.2 - 0.4mg sc stat dose or 0.8 - 2.4mg over 24 hours via syringe driver or hyoscine hydrobromide 0.4mg sc stat or 1.2 - 2.4mg sc over 24 hours via syringe driver.

Especially if element of pulmonary oedema, if antimuscarinics not effective consider use of parenteral diuretics. Furosemide can be given SC or via a 24 hour syringe driver.

Key information

Continuing Care

NHS Continuing Healthcare is the name given to a package of services, which is arranged and funded by the NHS alone for people outside hospital with ongoing care needs. Anyone can qualify for the package, regardless of location or diagnosis, provided they have a certain level of care needs. This means that a person's needs are such that they are still considered to be an NHS patient, even though they are not being cared for in a hospital.

At home, this means the NHS pays for:

- ❖ Healthcare (e.g. community nurse, specialist therapist or GP); and
- ❖ Personal care (e.g. personal carers, care workers).

In a care home, the NHS pays for care home fees (including board and accommodation).

Decisions about whether a person needs Continuing NHS Care are made by health and social services staff involved in the person's care, in consultation with the person, their carers and relatives. These people take part in a comprehensive assessment of the person's needs using formal assessment tools to work out which services and what support a person needs. This is sometimes referred to as 'the banding process'.

Most people who need Continuing NHS Care do so after having been cared for in hospital for an acute illness or accident. For this reason assessments usually take place when plans are being made for a person to leave hospital and it appears they still need ongoing help and support.

In 2007, The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care was published. This document suggests that there should be one national approach on determining eligibility, with a common process and national tools to support decision making.

Financial Benefits

Disability Living Allowance (DLA)

DLA can be claimed up to the age of 65. It is divided up into two components, care and mobility. The care component is for help with personal care and supervision, and the mobility component is for help with getting around. This allowance is paid at different rates depending on the person's needs.

DLA can be claimed even if the person is in paid employment. It is paid no matter what other income, benefits or savings a person has.

Attendance Allowance (AA)

AA is paid if a person is over 65 and needs regular help with personal care due to illness or disability. It can also be paid if a person cannot be left alone and needs regular supervision. There are two rates, lower and higher, depending on the level of care that is required. It is paid no matter what other income, benefits or savings a person has.

Special Rules

People with life-threatening illnesses may be able to apply for DLA or AA under special rules. It means they can get DLA or AA more quickly and easily, and will be paid at the higher rate. To apply under Special Rules a doctor's medical report, called a DS1500, is sent with the claim form.

Special rules can be claimed without telling the person affected this is being done. There is a tick box in the DLA/AA claim form that signifies when this is the case. The person receiving the benefit will receive a letter telling them about their DLA or AA but they will not be told anything about the Special Rules.

Appendix 1

TRIGGERS FOR REFERRAL OF PATIENTS WITH END STAGE HEART FAILURE TO SPECIALIST PALLIATIVE CARE

Specialist Palliative Care Teams within South West London accept and process referrals in a clear and equitable way. Any member of staff can refer to a specialist palliative care team after agreement by the patient and medical team (Consultant or GP).

Triggers for referral to Specialist Palliative Care Team include:

- ❖ Patient and medical team (Consultant or GP) aware of and agree to referral to specialist palliative care team.
- ❖ Patient is aware of their diagnosis of heart failure and the progressive nature of the disease has been discussed.

Plus the patient should meet two or more of the following:

- ❖ Patient has been assessed by health care team as having severe heart failure symptoms.
- ❖ It is anticipated that the patient is in the last 12 months of life.
- ❖ The patient continues to have complex symptom even after optimum heart failure treatment.
- ❖ The patient has had repeated hospital admissions with symptoms of heart failure.
- ❖ The patient / carer has emotional or spiritual needs relating to their progressive illness.
- ❖ There are issues relating to end of life planning e.g. preferred place of care, writing of wills, withdrawal of treatment.

Appendix 2

Diuretic Management in Worsening Heart Failure and Peripheral Oedema

Rationale

Daily weight ↑ > 1kg above dry weight

↑ Sustained over 2-3 days, with/without symptoms of

↑ dyspnoea and/or

↑ peripheral oedema

and stable blood chemistry

Increase Diuretics as follows:

Furosemide:

Current Dose	Increased to
40mgs od	80mgs od.
80mgs od.	80mgs am & 40mgs midday
80mgs am & 40mgs midday	80mgs bd

Bumetanide: (dose may be split am/pm)

Current Dose	Increased to
1mg od	2mgs od
2mg od	3mgs od
3mg od	4mgs od
4mg od	5mgs od

If an increased diuretic dose is sustained check U+Es if appropriate.

Tips for Management of Resistant Oedema

1. Ensure compliance with both medications and salt/fluid restriction.
2. Avoid NSAIDS as these will reduce diuretic effect.
3. Increase frequency of doses (to decrease the post diuretic salt retention period).
4. Furosemide absorption can vary between patients and bumetanide may be more predictable – particularly useful for converting from iv to oral medication where 40mg furosemide = 1mg bumetanide.
5. Combination with thiazide diuretics (bendrofluazide 2.5mg daily/metolazone 2.5mg alternate days or twice weekly) is usually effective in patients resistant to high dose loop diuretics
6. IV administration avoids problems with absorption
7. IV infusion even more effective than bolus (even at equivalent doses as no post diuretic salt retention)
8. In advanced chronic renal failure larger doses may be required than quoted above - as less diuretic is excreted into the urine where it has its effect - (up to 250mg furosemide bd may be required to achieve a diuretic effect)

Ultimately management needs to reflect the patient's wishes and the imminence of dying. Where a patient wants to be cared for / die at home, iv medications and daily weights will not be appropriate. Subcutaneous furosemide can be an option in the dying phase, where needed for symptom management and comfort.

Helpful Resources

Johnson M, Lehman R (eds) (2006) Heart Failure and Palliative Care: a team approach. Radcliffe Publishing Ltd, Oxon.

NHS Modernisation Agency (2004) Supportive and palliative care for advanced heart failure. Available at: www.heart.nhs.uk/serviceimprovement/1338/4668/palliative%20Care%20Framework.pdf

Watson M, Lucas C, Hoy A (2006) Adult Palliative Care Guidance (second edition). Available from The Princess Alice Hospice, Esher, Surrey.

National Institute for Health and Clinical Excellence., Chronic Heart Failure; Management of chronic heart failure in adults in primary and secondary care. 2003. National Collaborating Centre for Chronic Conditions: London

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Copies of the guidelines can be found on the SWL Cardiac Network website
www.southwestlondoncardiacnetwork.nhs.uk