

SYMPTOM CONTROL GUIDELINES
FOR PATIENTS WITH END-STAGE
HEART FAILURE
March 2007

Adapted from Merseyside & Cheshire Specialist Palliative Care
and Cardiac Networks

For the most up to date version go to
www.elmb.nhs.uk and click on 'Guidelines'.

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INTRODUCTION

According to the World Health Organisation, palliative care can be defined as:

“...an approach that improves the quality of life of patients and their families facing the problems associated with life threatening illness, through the prevention and relief of suffering by means of early intervention and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

The WHO also states that palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten nor postpone death;
- Integrates the psychological and spiritual aspects of patients care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated;
- Will enhance quality of life and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications;

(Sepulveda, C et al; 2002)

The National Council for Hospice and Specialist Palliative Services (2000) identify the key principles underpinning palliative care as:

- A focus on quality of life, including good symptom control;
- The whole-person approach, taking into account the patient's past life experience as well as their current situation;
- Care that encompasses both the person with life-threatening disease and those that matter to them;
- Respect for patient autonomy and choice (e.g. over place of care, treatment options, access to specialist palliative care);
- An emphasis on open and sensitive communications, which extends to patients, informal carers and professional colleagues;

Studies have indicated that patients with heart failure are often symptomatic, disabled and their symptoms have a significant impact on their lifestyle and quality of life (Anderson et al, 2001; McCarthy, Lay and Addington-Hall, 1996). Physical symptoms are frequently influenced by psychological, spiritual and social issues, hence the appropriateness of a holistic approach to care and the importance of the involvement of different members of the multidisciplinary team. Communication issues have also been highlighted to be of vital importance (Rogers et al 2000).

Referral to the Specialist Palliative Care Team should be considered if the patient or their carer has complex physical or psychological symptoms or needs which cannot be met by the team/s caring for them.

Quality End of Life Care (EoLC), which encompasses adequate control of physical and psychosocial symptoms, can be achieved through the use of the End of Life Tools. These are Gold Standards Framework (GSF), Preferred Place of Care (PPC) and Integrated Care Pathway (ICP) for the Last Days of Life. These tools were originally implemented for use with patients who had a cancer diagnosis. However all patients are entitled to receive a high standard of care at the end of their life which is co-ordinated and discussed with them.

Gold Standards Framework

This involves the GP practice holding a Supportive Care Register (SCR) for all patients who may be considered to be in the last 12 months of their life. These patients are then discussed at a regular GSF meeting with the GP, District Nurse and other appropriate healthcare professional. The principal of GSF is to be able to plan care in advance and prevent a crisis for the patient and their family which may result in not achieving their PPC.

Preferred Place of Care

The PPC is a patient held record which will follow the patient throughout their care in a variety of differing health care and social care settings. It can be issued any time from diagnosis, depending on the progress of the illness and assessment of the healthcare professional. An appropriate time may be when the patient is placed on the GSF register.

Integrated Care Pathway for the Last Days of Life

This has been developed to ensure the same standard of care is delivered to all patients who are in the last days of their life, regardless of diagnosis. It involves promoting good communication with the patient and family about death and dying as well as anticipatory planning of psychosocial and spiritual needs symptom control and care after death. There are symptom control guidelines to accompany the ICP.

For further information visit:

www.goldstandardsframework.nhs.uk

www.cancerlancashire.org.uk/ppc.html

[Frontpage - Marie Curie Palliative Care Institute Liverpool](#)

Patients may be referred by their General Practitioner or Consultant to the East Lancashire Heart Failure Nursing Service, for assistance with management, medication review, education and support. Community and Secondary Care clinics are held as well home visits for those at the end stage of heart failure. The service is also available for information and education to all health professionals.

Tel: 01254 734202/ 01200 420613

Symptom Control Guidelines in End Stage Heart Failure

- Symptom control should continue in conjunction with active cardiological management, including diuretics, ACE inhibitors etc as long as these medications remain appropriate.
- The holistic approach should be applied, considering physical, psychological, spiritual and social aspects.
- It is important to consider whether there are particular things worrying or frightening the patient and to explore the meaning of a symptom to the patient – for example, as pain or breathlessness worsens, do they assume “I am getting worse”?
- Involvement of all members of the multidisciplinary team, including physiotherapist, occupational therapist, social worker, psychologist, chaplain, may be appropriate.
- Optimum palliation of the symptoms of heart failure often depends on compliance with medication, especially with diuretics.
- In the event of deterioration of symptoms a treatable precipitant e.g. Non-compliance with medication, chest infection, anaemia, thyrotoxicosis, recent MI, arrhythmia, should be excluded.
- These palliative care guidelines focus on symptom control for patients with end stage heart failure and where appropriate should be used in conjunction with national and local guidelines for the management of heart failure, including NICE guidance (2003).

Breathlessness

Consider possible causes of breathlessness other than heart failure such as pharmacological causes e.g. Beta blockers, and psychological causes including anxiety.

Pharmacological management

- **Nebulised saline +/- bronchodilators e.g. Salbutamol 2.5mg or Terbutaline 2.5mg prn to qds.**
 - If co-existing angina, ensure availability of GTN spray as bronchodilators may precipitate angina in such patients.
 - Bronchodilators will not be effective if the patient is also taking Beta-blockers.
 - Consider monitoring serum potassium every 4 weeks, if appropriate.
- **Sublingual Lorazepam 0.5 - 1mg to max 4mg per day** - Especially if element of anxiety.
Diazepam 2mg orally can be considered as a second-line agent.
- **Low dose oral morphine – commencing at initial dose of 2.5mg 4 hourly**, titrating up every 48 hours as needed and tolerated
 - Immediate release morphine (e.g. morphine liquid) is often more effective for control of dyspnoea than sustained release preparations like e.g. MST® or MXL®).
 - Morphine is excreted renally, so if renal impairment or failure use a lower dose initially & reduce frequency to bd or tds depending on response.
 - Consider use of prophyllactic laxatives when commencing strong opioids.

In patients who are sensitive to morphine, alternative opioids may be suitable, and more advice regarding these can be obtained from the Palliative Care Team.
- **Fan**
- **Humidified oxygen – starting at 24% and continuing at this concentration if co-existent COPD.** Consider use of nasal specs
- **GTN spray 1 – 2 puffs prn.** Contraindicated in severe aortic stenosis.

Non - pharmacological management

- Dyspnoea management, including breathing retraining.
- Occupational therapy – lifestyle adjustments.
- Psychological support – appreciating impact on lifestyle.
- Anxiety management and education re management of panic attacks.
- Relaxation.
- Complimentary therapies.

Cough

Cough may be due to the underlying heart failure, and not due to ACE inhibitors, so these should not be automatically discontinued, especially in patients who have been taking them long-term. However, if an ACE inhibitor has been commenced recently and cough is also recent in onset, consider it as a *possible* cause and review.

- If related to difficulty expectorating – **Normal saline nebulas 2.5mls PRN.**
- Cough suppressants – **Low dose morphine liquid (starting dose 2.5mg-5mg every four hours, may also help SOB & pain)**

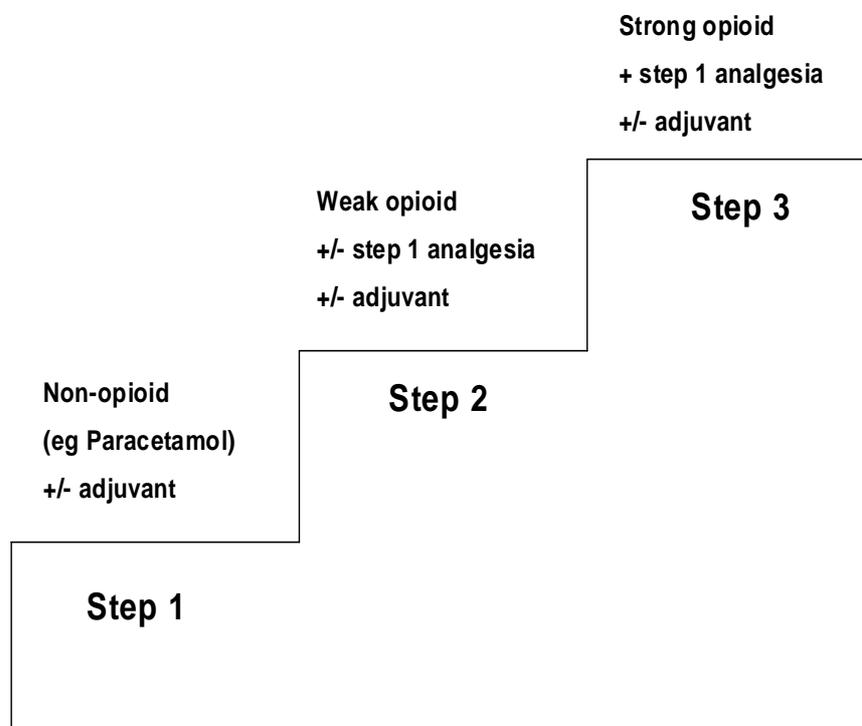
Consider use of prophylactic laxatives when commencing strong opioids.

For alternative options if the above are not effective consider referral to Specialist Palliative Care.

Pain

A high proportion of heart failure patients experience pain, up to 78% in some studies. This may include non-specific generalised pain including musculoskeletal.

- Need to consider psychological, emotional & spiritual aspects – pain may be affected by patient's mood, what the pain signifies to the patient (e.g. Progression of their illness)
- Importance of other team members – Physio, OT, DN, specialist nurses, social worker, psychologist, chaplain.
- Need full assessment of pain, site, possible cause etc. Remember to consider other causes and pathologies in addition to heart failure.
- Analgesic ladder (WHO):



For STEP 3

- **Commence oral morphine at a dose of 2.5mg up to 4 hourly;** titrate up as necessary. Low dose oral morphine may help breathing as well as pain.
- Reduce dose frequency in renal impairment. If renal function is marked impaired, contact Specialist Palliative Care Team for advice regarding opioids.
- When commencing strong or weak opioids consider use of prophylactic laxatives.
- Anti-angina medication if angina.
- Non-steroidal anti-inflammatory agents including COX II inhibitors can worsen heart failure so should be used with caution.

Nausea and Vomiting

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

- Consider drug cause for nausea and vomiting.
- If constant nausea, drug induced nausea, renal impairment or renal failure.
Haloperidol 1.5 – 3mg orally or subcutaneously at night.
- If related to meals, early satiety, vomiting of undigested food, hepatomegaly,
Metoclopramide 10mg orally or subcutaneously three times daily
Domperidone 10mg-20mg orally 3-4 times daily (cannot be given via syringe driver)

As a second or third line alternative, **replace** other anti emetics with:
Levomopromazine 6.25mg orally or subcutaneously at night and when required – may also have anxiolytic effect

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

Avoid Cyclizine as this may worsen heart failure.

Cachexia and Anorexia

Patients with heart failure may have poor appetite and lose significant amounts of weight. The focus of earlier dietary advice may need to be advised 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.
- For additional guidance for those at additional risk please go to http://www.elmmb.nhs.uk/Food_First_Guidelines.pdf
- Consider referral to dietician.

Constipation

- May be triggered by reduced intake of fluids and food, diuretics, immobility, weak or strong opioids (NB consider prophylactic laxatives when commencing these).
- May need stool softener (e.g. Sodium docusate 100-500mg daily in divided doses)
- Stimulant laxative (**e.g. Senna 2 tablets or 10mls once to twice daily**) used with an osmotic laxative (**e.g. Lactulose 10 - 20mls twice daily**). Or a combined stimulant and softener (**e.g. Codanthramer 2 capsules once to twice daily or 10ml once to twice daily**) – this is licensed for use in terminal illness only.
- Other options for constipation include Movicol® (Osmotic laxative) 1-2 sachets daily for maintenance, dissolve in 125mls water. Caution in heart failure - should not take more than 2 sachets in any 1 hour.
- For additional guidance please go to http://www.elmmb.nhs.uk/Food_First_Guidelines.pdf

Psychological Issues

Psychological issues and factors contributing to these include:

- **Low mood**
- **Depression**
- **Insomnia**
- **Anxiety**
- **Fatigue and lethargy**
- Medication should be considered including:
 - **Antidepressants.** Avoid tricyclic antidepressants and venlafaxine in view of cardiotoxic side effects.
 - **Sertraline 50mg daily** is a suitable first line agent unless anxiety/panic disorder is present in which **Citalopram** would be appropriate (initially **10mg daily, then increased to 20mg daily** after 7 days).
Mirtazepine 15mg nocte (increasing to 30mg in 2-4 weeks) is another alternative especially if nausea or poor appetite are associated problems.

Night sedation e.g. Temazepam 10-20mg nocte or Zopiclone 3.75mg-7.5mg nocte

Anxiolytics - Lorazepam 0.5-1mg orally or sublingually, or diazepam 2mg orally for generalised anxiety disorder can be used in the short term. Consider use of Citalopram for both panic disorder and generalised anxiety management (as detailed above)

However 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 may be helpful to explore what the patient thinks is preventing them from sleeping, what makes them anxious, why they feel low.

Restless legs –Diagnosis of restless legs syndrome (RLS) can be made if all of the following four criteria are met:

- a need to move the legs, usually accompanied or caused by uncomfortable, unpleasant sensations in the legs.
- Symptoms are exclusively present or worsen during periods of inactivity/rest.
- Symptoms are partially or totally relieved by movement such as walking or stretching at least as long as the activity continues
- Symptoms are generally worse or exclusively occur in the evening or during the night.

Patients with moderate to severe RLS (as rated on the IRLS scale, 15 to 40 points) should also be offered sleep hygiene advice and non-pharmacological measures. Patients may consequently be offered treatment with pramipexole (as per the BNF), which may be initiated by any prescriber for the treatment of restless leg syndrome (RLS) when iron deficiency and other causes have been excluded. Treatment should be reviewed at 3 months and stopped if little or no benefit seen. Patients should be referred where there is neurological co morbidity (if this requires assessment or seriously impedes diagnosis), failure of response to two dopamine agonists, or augmentation occurs.

Peripheral Oedema

May include arms and genitalia as well as lower limbs.

- Diuretics.
- Dry skin – medium emollient Diprobase® cream, heavy emollient Hydromol® cream (see East Lancs Joint Medicines Formulary for other choices)
- Pruritus – Crotamiton 10% cream or lotion (Eurax®), or second line menthol 1% in aqueous cream 500gram (Arjun® 1% cream).
- Compression bandaging – input from District Nurse, lymphoedema nurses, tissue viability nurses.
- Scrotal support for scrotal oedema.
- OT assessments – need to adjust expectations of patient and carer.
- Social worker – services at home.

Dry Mouth

Assess for underlying cause.

May be due to oxygen therapy, medication, underlying oral thrush.

- Ice cubes
- Chewing gum
- Pineapple juice
- Biotene Oral balance® gel or Glandosane® spray (Prescription must be endorsed 'ACBS')
- Chlorhexidine 0.2% mouthwash or 1% gel
- For additional guidance please go to http://www.elmmb.nhs.uk/Food_First_Guidelines.pdf

Withdrawal of Medication

When considering the withdrawal of therapy the question of whether the burden of taking a therapy outweighs the benefits should be considered in each case. As every patient will have different needs and problems this information is designed to be a guide rather than being an absolute rule about the order in which to consider withdrawing therapy.

Cholesterol lowering drugs (e.g. statins) are usually amongst the first to be discontinued when the amount of medication taken has become an issue. This is 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 beta blocker is also helping angina symptoms it may be best to keep it going. 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. Anti platelet agents are typically given to lower the risk of ischemic events (angina/MI). If symptoms are stable and the prognosis is poor from the heart failure these need not be continued. Anticoagulants (Warfarin) are mainly given to lower the longer-term stroke risk. The decision to stop Warfarin requires (even) more discussion. Some patients do not wish to carry on having repeated blood tests to monitor INR control. Tinzaparin (prophylactic or treatment doses) can be an alternative.

Finances/Benefits

The range of benefits available to patients and carers is extensive, and a full assessment is recommended, advice is available from the Welfare Rights Team for the various locations.

Welfare Rights Burnley and Pendle 19/21 Carr Road, Nelson BB9 7JS Tel 01282 66133

Welfare Rights Hyndburn Ribble Valley, and Rossendale 6/8 Birch Street, Accrington BB5 1LG Tel 01254 301141

Advice and Information Centre 3/5 Salford, Blackburn, BB1 6HG Tel 01254 692532/698312

Key Benefits are listed below

- **Disability Living Allowance (DLA)** (if <65 years, need help getting around, help with personal care or help with both)
- **Attendance Allowance (AA)** (if > 65 years, if need help with personal care)
- Normally help should be required for at least 6 months before becoming eligible for either of these benefits.

Special rules for Disability Living Allowance or Attendance Allowance – high rate of allowance if prognosis < 6 months. For a patient to claim this, the DS1500 and mobility component of Disability Living Allowance application should be completed. If a patient is eligible under the special rules they do not need to require help for more than 6 months to be entitled to Attendance Allowance.

A patient is eligible for free prescriptions if unable to get out without the help of another person. To apply for a NHS Medical Exemption Certificate, ask the receptionist at the GP surgery for a form. The surgery will endorse the completed application and send it to the Prescription Pricing Authority and a certificate should be sent to you within 14 days.

Travel abroad should only be considered with full insurance for patients with end-stage heart failure and difficulty may be encountered when seeking this. Advice regarding suitable companies can be obtained from CANCERBACUP and from hospice information service www.cancerbacup.org.uk Tel 0808 0800 1234

The Citizens Advice Bureau (CAB) and the Disability Benefits helpline (0800 882200) are useful resources for advice and information regarding practical issues including finance.

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 team about the patient's condition.
- 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. 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.

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.
- As the patient becomes weaker and has difficulty swallowing, need to discontinue non-essential medications, but continue those that will provide symptomatic benefit.
 - Such essential medications as analgesia, anti-emetics, anxiolytic, and opioids can be converted to subcutaneous doses if appropriate given continuously over 24 hours via syringe driver with as required doses if needed.
 - Should discontinue such inappropriate invasive procedures as venepuncture and checking of temp, BP etc. Need to establish inappropriateness of CPR; may also need to discuss with patient and family stopping of intravenous hydration. 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 (Please contact your heart failure specialist nurse to arrange this).
 - Similarly, if they have an epidural implant it is important to consider when it would be appropriate to stop topping this up.
 - Need regular assessment of symptoms & adjustment of medications if symptoms are not adequately controlled.
 - Psychological support of patient & family very important. Good clear but sensitive communication of paramount importance.
 - Spiritual care according to patient's cultural and religious beliefs is important.

Please consider commencing the Integrated Care Pathway (ICP) for Last days of Life and refer to the Guidelines for the Management of Symptoms in the Last Days of Life for further symptom management.

For further information visit:

www.goldstandardsframework.nhs.uk

www.cancerlancashire.org.uk/ppc

www.mcpil.org.uk

Withdrawal of Device or Implantable Cardioverter Debrillator Therapy (ICD)

Defibrillators are increasingly commonplace in the care of heart failure especially those combined with cardiac resynchronisation pacing (CRT). Withdrawal or deactivating implantable defibrillators can be difficult for patients and their relatives and should be addressed on an individual patient basis. Patients often report a perceived dependence on the device. Not all deaths from heart failure result in tachyarrhythmia as final mode of death

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 heart failure.

ICD patients should be encouraged to express their concerns especially in relation to their mode of death and shocks.

Where to 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 CRT can be left active with tachyarrhythmia therapies turned off

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 discussed if being discharged from hospital to palliative community care it is incompatible that a patient should have a active ICD but otherwise be not for resuscitation.

Defibrillator clinic and specialist nursing staff should be liaised with along with the supervising electro physiologist/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 informed as the device requires deactivation before removal by mortuary or undertaker staff. Relatives should be made aware cremation is not possible with an ICD in situ.

Contributors

Content adapted from:

**The Cheshire and Merseyside CHD Collaborative and Cancer Network Guidelines (2005)
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