



Cheshire and Merseyside  
Cardiac and Stroke Networks

# **SYMPTOM CONTROL GUIDELINES FOR PATIENTS WITH END-STAGE HEART FAILURE AND CRITERIA FOR REFERRAL FOR SPECIALIST PALLIATIVE CARE**

***Working Party of the Merseyside  
and Cheshire Specialist Palliative Care and  
Cardiac Clinical Networks***

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## INTRODUCTION

The following guidelines were developed in 2005 and have now been revised. They are to be used as a guide to support health care professionals to manage care of heart failure patients who are entering the later stages of their condition. The emphasis is on symptom control.

They are designed to be complementary to standard cardiological treatment and it is important to consider whether adjustments to standard treatments are required.

They do not replace other local/national guidelines and are to be used in tandem with them.

# PALLIATIVE CARE IN HEART FAILURE

According to the World Health Organisation (2002), 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 patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the 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.

(Sepúlveda, C *et al*; 2002)

The National Council for Hospice and Specialist Palliative Care Services (2000) identifies 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 who 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 communication, 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).

Within the Merseyside and Cheshire region, a working party comprised of specialists from palliative care and cardiology was set up. This multiprofessional group aimed to formulate symptom control guidelines for health care professionals caring for patients with end-stage heart failure, focussing on those symptoms that are particularly common or especially troublesome in this patient group. The working party has also developed referral criteria to facilitate the identification of those end-stage heart failure patients for whom referral to Specialist Palliative Care would be appropriate. The guidelines and referral criteria are presented here, along with relevant references.

## TASK GROUP

### The following professionals were involved in the 2009 revision of the guidelines

Christine Gardner	Clinical Lead Nurse for Cheshire and Merseyside Cardiac Network
Dr Clare Littlewood	Macmillan Consultant, Palliative Medicine, St Helens and Knowsley Hospitals NHS Trust
Dr Jenny Smith	Consultant, Palliative Medicine, Countess of Chester NHS Foundation Trust
Dr Graham Whyte	Specialist Registrar, Palliative Medicine, St Helens and Knowsley Hospitals NHS Trust
Barbara Flowers	Heart Failure Nurse Specialist, Southport and Ormskirk NHS Trust
Rebecca Telfer	Palliative Care/Heart Failure Nurse Specialist, Halton and St. Helens PCT
Sarah O'Hare	Community Heart Failure Nurse Specialist, Knowsley PCT

The following health care professionals have reviewed and added to the guidelines....

Dr Kamesh Pulya	Consultant Cardiologist, Southport and Ormskirk NHS Trust
Dr Jonathan Fox	Consultant Cardiologist, Southport and Ormskirk NHS Trust
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Dr Peter Mennim	Consultant Cardiologist, Southport and Ormskirk NHS Trust
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Dr Jon Somauroo	Consultant Cardiologist, Countess of Chester Hospitals NHS Trust
Andrew Dickman	Senior Pharmacist, Liverpool Marie Curie Institute
Barbara Perry	Lead Pharmacist Medicines Outcomes, Western Cheshire PCT
Pauline Roberts	Pharmacy Advisor Care Homes, Western Cheshire PCT

# GUIDELINES FOR REFERRAL TO SPECIALIST PALLIATIVE CARE

**(All at the discretion of the referrer and in conjunction with clinical assessment)**

**CRITERIA FOR REFERRAL TO SPECIALIST PALLIATIVE CARE include**

Patient and medical team (consultant or GP) aware of and agree to referral to specialist palliative care

**PLUS TWO OR MORE OF THE FOLOWING:**

1. Patient knows that they have a confirmed diagnosis of heart failure
2. Advanced heart failure (New York Heart Association Grade 3 or 4 \* at discretion of health care team or cardiology team) on optimal medical therapy who are not candidates for revascularisation (cardiac re-synchronisation therapy (CRT) non cardiac transplantation).
3. Anticipated last 12 months of life
4. Three admissions to hospital within the last 12 months with symptoms of decompensated heart failure
5. Physical or psychological symptoms despite optimal tolerated therapy (+/- deterioration in renal function)

*\* New York Heart Association Grade 3 or 4 – marked dyspnoea on ordinary or any exertion or symptoms at rest*

## SYMPTOM CONTROL 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 with a patient – for example, as pain or breathlessness worsen, 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 management of heart failure, including NICE guidance (2003).

# 1. 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

- **Oxygen** (humidified if possible) – can be started at a prescribed level determined at time of assessment and taking into account co-existing respiratory conditions. Consider use of nasal specs.

### Home Oxygen Service

The Department of Health document Home Oxygen Service was last modified in March 2007. Information for patients, relatives and carers can be found on the NHS website at: <http://www.homeoxygen.nhs.uk>

- GPs can prescribe oxygen for symptomatic relief in palliative care.
- District nurses are able to authorise oxygen therapy at home by following local arrangements for the assessment and prescription of oxygen.
- Risk assessment is needed regarding any safety hazards that may be present, for example trip hazard from oxygen giving set. Patients and relatives must be aware that it is essential they refrain from smoking in the same room as the oxygen cylinder.
- The supplier for the North West of England is currently Air Products. Fax: 0800214709 and Telephone: 0800-373580.
- Home Oxygen Order Form (HOOF) must be completed and faxed to the supplier.
- The supplier will deliver the oxygen cylinder to the patient's home within four hours if ordered as an emergency. The emergency order is valid for three days, therefore, a non emergency HOOF must be completed as well if the oxygen is required for more than three days.
- The supplier invoices the PCT, therefore, the Medicines Management Team must be informed of the order.
- The GP must be informed of the order if they have not been the prescriber.
- When the oxygen is no longer required the supplier should be informed immediately so that the contract is cancelled and collection of equipment can be arranged. The PCT will continue to be charged for oxygen concentrators that have not been cancelled.
- In some areas, the fire and rescue advocacy service will do a home risk assessment.

Contact numbers: - Merseyside: 0800-731-5958 Ref: 244  
Cheshire: 01606-868656

**Low dose Oramorph – an initial stat dose 2.5mg can be tried**, then 2.5mg four-hourly, titrating up every 48 hours as needed and tolerated.

- Rapid release more often effective for control of dyspnoea than sustained release (MST, MXL).
- If there is renal impairment use lower dose initially.

- Consider use of prophylactic 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.
- GTN spray 1-2 puffs p.r.n. Contraindicated in severe aortic stenosis.
- Nebulised 0.9% saline +/- bronchodilators eg 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 less effective if the patient is also taking  $\beta$ -blockers. Consider monitoring serum potassium every four weeks, if appropriate.
- Sublingual lorazepam 0.5 – 1mg prn to max 4mg per day, especially if there is an element of anxiety. Diazepam 2mg – 5mg BD is longer acting and can be considered as second-line agent. This effect may be useful but can accumulate in hepatic impairment.

#### **NON-PHARMACOLOGICAL**

- Dyspnoea management, including breathing retraining, especially if hyperventilation is a problem.
- 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.
- Use of recliner bed.

## 2. FATIGUE AND LETHARGY

This is extremely common and very difficult to treat symptomatically.  
Common causes are:

- Low cardiac output or low BP: seek advice of the heart failure team re possible addition of digoxin (low dose) or reduction of beta blocker, Angiotensin Converting Enzyme inhibitor (ACEI)/Angiotensin II Receptor Antagonist, 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 – adjust dosage and frequency.
- Anaemia consider investigation/ treatment by heart failure team.
- Hyponatraemia/ hypokalaemia - check urea and electrolytes
- Hypothyroidism – check Thyroid Function Test

Consider lifestyle adaptation/OT assessment re aids/appliances/nutritional support.

Refer cardiac/heart failure rehabilitation programme if available.

## 3. COUGH

- **Productive Cough**

- Consider usual causes such as lower respiratory tract infection or worsening pulmonary oedema.

- **Non Productive Cough**

If an ACE inhibitor has been commenced recently and cough is also recent in onset, consider it as a possible cause and refer to healthcare professional managing their heart failure treatment.

If cough is longstanding it is unlikely to be due to ACE inhibitors. Do not stop automatically and refer to the heart failure team.

If cough continues, consider the following:-

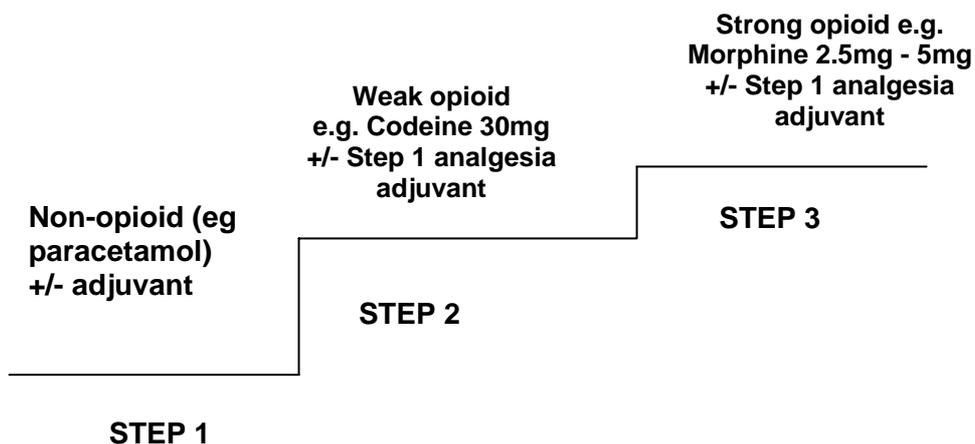
- If related to difficulty expectorating – **0.9% saline nebulules 2.5mls PRN.**  
(amount actually absorbed when nebulised minimal)
- Cough suppressants/ expectorant – **Simple linctus 5 - 10mls PRN to qds**
  - **Codeine linctus 5 – 10mls PRN to qds**
  - **Low dose oramorph** starting dose **2.5mg**, every four hours as tolerated (may also help SOB and 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.

## 4. 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 and 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 – physiotherapy, 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 oramorph at dose of 2.5mg up to four- hourly**, titrate up as necessary. Low dose oramorph may help breathing as well as pain.
- Reduce dose frequency in renal impairment. If renal function is markedly impaired, contact the Specialist Palliative Care Team for advice regarding alternative opioids.
- When commencing strong or weak opioids, consider use of prophylactic laxatives.
- Anti-anginal medication if angina.
- **Non-steroidal anti inflammatory agents/COX2 inhibitors should be avoided if at all possible as they worsen heart failure.**  
If burden of pain outweighs risk of treatment they should be used with caution and full explanation given.

- Gout is also very common and often due to diuretic therapy.
- Use colchicine first line 500 microgram b.d to q.d.s until pain relieved or vomiting or diarrhoea occur.
- Diuretic therapy SHOULD NOT be discontinued. Consider dose reduction – seek advice from the heart failure team.
- Allopurinol should NOT be commenced in acute attack as it may prolong pain or precipitate a further acute attack.
- In patients already on allopurinol therapy, it should be continued alongside conventional treatment of acute attack.

### **Management of Chronic Gout**

Consider starting allopurinol 1-2 weeks after acute attack has settled.

Start 50-100mg day.

Colchicine should be given 500 microgram daily during initiation to reduce risk of acute attack.

Maintenance dose of allopurinol. 100 – 300mg daily.

Doses need to be lowered according to renal function.

<b>Estimated GFR of Allopurinol</b>	<b>Usual Maintenance Dose</b>
>80 ml/min	200-300mg daily
60-80 ml/min	100-200mg daily
30-60 ml/min	50-100mg daily
15-30 ml/min	50-100mg alternate days
On Dialysis	50- 100 mg weekly

## 5. NAUSEA AND VOMITING

Patients with advanced heart failure may have multiple causes of nausea and vomiting. Anti-emetics should be given regularly and not PRN

- Consider drug cause for nausea and vomiting.
- If constant nausea or if renal impairment or renal failure,  
**haloperidol 1.5mg - 3mg orally/SC nocte. If converting to SC route the dosage is halved i.e. 3mg orally = 1.5mg SC.**  
**Low dose Levomepromazine 3mg – 6mg, if converting to SC dose 6.25mg is used.**
- If related to meals, early satiety, vomiting of undigested food, hepatomegaly or liver congestion,  
**metoclopramide 10mg po/SC tds.**  
**domperidone 10mg po tds**

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 injections or by continuous subcutaneous injection (via syringe driver) , as oral anti-emetics may not be adequately absorbed.

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

## 6. CACHEXIA AND ANOREXIA

Patients with heart failure may have 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 heart failure at risk of malnutrition. An unintentional weight loss of 10% in 3-6 months is indicative of malnutrition.

The focus of earlier dietary advice may need to be revised on the basis of reassessment. Avoid steroids for treatment of anorexia.

Dietary advice can be confusing to this group of patients; they may be following low fat or "diet" programmes which may be 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 what ever they want. Encourage small frequent meals and snacks. 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 this can be relaxed to improve intake. Patients may need assistance with cooking and shopping. Use of oral nutritional supplemental drinks may be appropriate. Referral to dietician for advice would be beneficial.

## 7. CONSTIPATION

- May be triggered by reduced intake of fluids and food, diuretics, immobility, weak or strong opioids (NB consider prophylactic laxatives when commencing these).
- It may be necessary to use a faecal softener, a stimulant laxative or a combination product of the two.
- Doses given below are those in the BNF, but higher doses may be needed in palliative care patients.

### Faecal softener

- **Sodium docusate** – up to **500mg daily** in divided doses.
- **Lactulose solution** – initially **15mls twice daily**, adjusted according to the patient's needs.
- **Movicol® sachets** – **1 – 3 sachets daily** in divided doses usually for up to 2 weeks. The contents of each sachet should be dissolved in half a glass (approx 125ml) of water. Maintenance dose **1-2 sachets daily**. (Caution may be needed due to the fluid volume and sodium content.)
- **Idrolax® sachets** – **1-2 sachets** has less sodium content.
- **Magnesium hydroxide** – **25mls – 50mls** when required. This may be useful in resistant cases and may be also help to relieve co-existing gastric symptoms. However, care is needed in patients with moderate or severe renal impairment.

### Stimulant laxatives

- **Senna 2** – **4 tablets, usually at night**. Initial dose should be low then gradually increased.

### Combination of softener and stimulant

- **Codanthramer (danthron and poloxamer)** – **1 – 2 capsules** or **5mls–10mls** of solution (**25/200 in 5mls**) **at night**.
- **Codanthrusate (danthron and docusate)** – **1 – 3 capsules, usually at night**, or **5mls–15mls of suspension at night**.

The use of these is only licensed in terminal illness.

## 8. PSYCHOLOGICAL SYMPTOMS

Psychological issues and factors contributing to these include:

- **Low mood**
- **Depression** – of which there is high incidence, at least 1/3 of heart failure patients. Suggest use of appropriate screening tool e.g. PHQ9.
- **Insomnia**
- **Anxiety**
  
- Medication should be considered including
  - **Antidepressants.**  
Avoid tricyclic antidepressants in view of cardiotoxic side-effects. **Sertraline 50mg** is a suitable first-line agent unless anxiety/depression in which case **citalopram 10mg–20mg** daily would be appropriate. Check for hyponatraemia if appropriate. **Mirtazapine 15mg–30mg nocte** is another alternative especially if nausea or poor appetite are associated problems.
  
  - **Night sedation** - eg **Lorazepam 0.5mg – 1mg nocte**  
**Temazepam 10mg- 20mg nocte**
  
  - **Anxiolytics** **Lorazepam 0.5mg–1mg nocte s/l**  
especially for panic attacks  
**Diazepam 2mg po** – for anxiety

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.

## 9. PERIPHERAL OEDEMA

Peripheral oedema in heart failure is often secondary to right heart failure as a direct consequence of left heart failure (congestive cardiac failure). There are also other causes including dependent oedema from immobility and side effects from medication e.g. Amlodipine. Complications can include leg ulceration, pressure sores, stasis eczema and cellulitis. It can range from very mild dependent ankle oedema to very severe associated with ascites, scrotal oedema and thoracic oedema (anasarca).

- First line treatment of peripheral oedema secondary to fluid accumulation from heart failure is diuretic therapy. Frusemide may not be absorbed as there may be associated gut oedema. Bumetanide tends to be absorbed better. Intravenous diuretics may be necessary. A Frusemide infusion (250mg/150mls @ 2mls/hour) is an excellent way of removing fluid overload and is more effective than bolus Frusemide injections.
- Pruritus/dry skin – aqueous cream + 0.5% menthol may be useful.
- Compression bandaging – input from DN, lymphoedema nurses, tissue viability nurses as appropriate.
- Scrotal support for scrotal oedema.
- OT assessments – need to adjust expectations of patients and carers.
- Social worker – services at home.
- District nursing team may review need for further equipment at home e.g. pressure relieving mattress, profiling bed and refer to others e.g. tissue viability nurse.

## 10. DRY MOUTH

Assess for any underlying cause.

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

- Ice cubes
- Chewing gum
- Pineapple juice/ chunks
- **Oral balance gel** - requires `ACBS` on a prescription
- **Saliva orthana oral spray, Glandosane, BioXtra, Salivese, Salivix** – these are only licensed for dry mouth due to radiotherapy or Sicca syndrome and require `ACBS` on a prescription.
- **Luborant** – licensed for all causes of dry mouth.

Consider underlying treatable causes e.g. oral thrush (especially if risk factors such as recurrent antibiotics, corticosteroids)

## 11. WITHDRAWAL OF MEDICATION

As the patient's condition deteriorates and their prognosis is reduced to weeks, it may be appropriate to consider withholding or stopping some medication. Often heart failure patients have polypharmacy issues, and any non-essential medication may be withdrawn, minimising side effects and number of tablets to swallow.

- Statin therapy can be stopped as the rationale is to reduce cardiovascular disease events and total mortality. Cholesterol is not an issue at this stage, and many patients may be cachexic.
- $\beta$ -blocker therapy may be reduced or stopped as they may depress the myocardium further, but reassess if arrhythmias are suspected.
- If blood pressure is low or renal function poor, then reassess the need for ACE Inhibitors/Angiotensin receptor blockers.
- If no evidence of angina, review the need for nitrates and other anti-anginals, such as Nicorandil or calcium channel blockers e.g. Amlodipine – especially if activity is minimal and BP may be low. If symptoms recur then can reintroduce.
- Aspirin may cause gastric irritation, especially as oral intake may be poor.
- Warfarin therapy is monitored by invasive blood tests and may be stopped.
- Other forms of medication used for other co-morbidities may be withheld or stopped such as osteoporotic medication.

**Diuretic therapy should be maintained as needed for symptom control, given via an appropriate route.**

Giving Frusemide has been shown to be effective when given subcutaneously in healthy volunteers. One survey showed it was used by up to 60% centres caring for an elderly population but its effectiveness was not examined.

Dose used subcutaneously is same dose as intravenous unless there is a reaction at site of administration that prevents absorption

Dose can be given as stat or via continuous subcutaneous infusion.

It can be infused over 24hrs, mixing with water. There is limited data on drug compatibility so it is not recommended to mix with any drugs. The subcutaneous route is unlicensed.

## 12. INTRODUCTION OF IMPLANTABLE CARDIOVERTER DEFIBRILLATORS (ICDs)

Many patients across Cheshire and Merseyside have undergone a cardiac procedure which gives them an **Implantable Cardioverter Defibrillator (ICD)** device. This intervention is performed in order to prevent sudden cardiac death from certain life threatening arrhythmias. The implant can detect such an event, and it is programmed to deliver an internal shock to the myocardium, to try and restore a normal cardiac rhythm.

Sometimes, an ICD may be combined with a special type of pacing device, but this type of device is not used in every patient.

There are devices which pace the atrium, and others which synchronise the way in which both ventricles beat together; i.e. bi-ventricular pacing, better known as Cardiac Resynchronisation Therapy (CRT ). Some will just have the ICD on its own.

Deactivation of the ICD is necessary when it is deemed no longer appropriate for shocks to be delivered to the heart. This is especially so when a patient nears the end of life with advancing disease.

Across Cheshire and Merseyside, the situation regarding the need for deactivation has been recognised, and work was undertaken to complete a protocol (Oct 2007) to help patients and staff reach this decision, at the right time for the patient. It also supports the required actions to undertake deactivation of the ICD device, when this decision is reached.

To reiterate:

*"The decision to withdraw the ICD therapy must be made by the doctor in charge of the patient's care in consultation with the multidisciplinary team, and having first obtained a competent patient's consent. If the patient lacks the capacity to consent, the doctor must consider whether there is a valid and applicable advance decision in force and /or whether there is an Attorney who has been appointed under a Lasting Power of Attorney (LPA) ( Mental Capacity Act 2005,) who can give consent to withdrawal. If neither is in place, the decision must be made on the basis of the patient's "best interests" having first complied with the statutory duty to consult those closest to the patient, and those with a proper interest in their welfare e.g anyone providing care to the patient on an unpaid basis. If there is no-one with whom it is practical and/or appropriate to consult, an Independent Mental Capacity Advocate (IMCA) must be consulted instead, and their view taken into account before a decision on best interests is reached." (CMCN 2007)*

For further information, please consult the **CMCN Document "The Decision to withdraw Implantable Cardioverter Defibrillator (ICD) Therapy in an Adult Patient"**.

Deactivation decisions on patients should be made in a timely fashion and preferably performed in a clinic setting. If this is not possible, in Cheshire and Merseyside, the local DGH cardiac physiology staff have been trained to support the process in a community setting, and local hospital department leads should be contacted for help with this support.

## 13. FINANCIAL BENEFITS

- **Disability living allowance (DLA)** (if < 65 years, need help getting around, help with personal care or help with both)
- **Attendance allowance (AA)** (if  $\geq$  65 yrs, if need help with personal care)
- Normally help should be required for at least six months before becoming eligible for either of these benefits

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

A patient is eligible for free prescriptions if they have a continuing physical disability which means that they are not able to go out without the help of another person.

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 BACUP and from the Hospice Information Service (Myers, 2002). Advice about travelling abroad with controlled drugs is available on the website [www.aintreehospitals.org.uk](http://www.aintreehospitals.org.uk) .

The Citizens Advice Bureau (CAB) is a useful resource for advice and information regarding practical issues including finance. The Disability Benefits Helpline (0800882200) may also be helpful.

## 14. SPIRITUAL SUPPORT

This should be assessed for all patients.

## 15. TERMINAL HEART FAILURE

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. In primary care it is good practice to work within the Gold Standards Framework (GSF). Patients with advanced stage heart failure should be identified on the supportive register and discussed at practice meetings on a regular basis.

Further advice available on prognostication – prognostic indicator guidance on GSF website

It is often more difficult to diagnose the terminal phase of heart failure than cancer, however:-

- Need agreement within the team about the patient's condition.
- It is often difficult to accept 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 the palliative phase.

If recovery is 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 two to three days to appropriate change in diuretic or vasodilator drugs
  - Sustained hypotension
- As patient becomes weaker and has difficulty swallowing, there will be a need to discontinue non-essential medications, but continue those which will provide symptomatic benefit.
  - Such essential medications as analgesia, antiemetics, anxiolytics and opioids can be converted to subcutaneous doses, if appropriate given continuously over 24 hours via syringe driver with as required doses available if needed.
  - Should discontinue such inappropriate invasive procedures as venepuncture and checking of temperature, blood pressure etc. Need to establish inappropriateness of CPR, and may also need to discuss with patient and family stopping of intravenous hydration.
  - Need regular assessment of symptoms and adjustment of medications if symptoms not adequately controlled.

- Psychological support of patient and family is very important. Good, clear but sensitive communication is of paramount importance.
- Spiritual care according to patient's cultural and religious beliefs is important.
- Ideally, whenever possible, the patient's terminal care should be facilitated within the setting of their choice, and in accordance with the wishes of the patient and family. Use of the documents 'Preferred Priorities for Care' (PPC) and 'Gold Standards Framework' (GSF) and Liverpool Care Pathway (LCP) may promote this. Further information is available on the EOL website – ([endoflifecare.nhs.uk](http://endoflifecare.nhs.uk)).

## 16. CARER/BEREAVEMENT SUPPORT

Contact local specialist services for advice.

### **BREATHLESSNESS**

**Diamorphine or Morphine at initial dose of 1 – 2.5mg sc 4 to 6 hourly if patient has not been taking oral morphine.**

If patient is on oral morphine or other strong opioid, seek advice of Palliative Care Team regarding appropriate starting dose of morphine. If effective, consider commencing syringe driver with morphine/ diamorphine, dose dependent on the amount of oral morphine and sc doses required in previous 24 hours.

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

### **PAIN**

**Diamorphine 1mg - 2.5mg or morphine 2.5mg – 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 strong opioid

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

### **AGITATION, TERMINAL RESTLESSNESS**

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

**Midazolam 2.5mg – 5mg sc four hourly**. If repeated doses required, consider commencing syringe driver with dose dependent on requirements of previous 24 hours.

**Morphine/Diamorphine alone is not appropriate**

### **NAUSEA AND VOMITING**

**Haloperidol 2.5mg - 10mg over 24 hours via syringe driver**

**Levomopromazine 6.25 -12.5mg over 24 hours via syringe driver or 6.25mg sc as a stat.**

### **RETAINED SECRETIONS IN UPPER RESPIRATORY TRACT**

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

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

Especially if element of pulmonary oedema, if antimuscarinics not effective consider use of parenteral diuretics.

**SC dose of furosemide = IV dosage via separate syringe driver mixed with water**

## MEMBERS OF THE WORKING PARTY 2005

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