Guidelines for Symptom Control and Specialist Palliative Care Referral For Adults Patients with End-Stage Heart Failure
1. Background

The palliative care needs of patients living with heart failure have recently been recognised as being as significant as patients living with cancer. Indeed the prognosis for patients with a diagnosis of heart failure is often shorter than for many cancer patients.

Nationally in recognition of this, considerable effort has been put into developing services which are more appropriate for the needs of this group; locally the Guys and St. Thomas’ charity funded a study to look at the needs of heart failure patients at Guy’s and St. Thomas’ NHS foundation Trust (GSTTFT).

Local guidelines for GSTTFT were produced as a response to that piece of work in order to better equip trust health professionals working with heart failure patients, so that they can be more responsive to the palliative care needs of their patients.

This document was adapted from these GSTTFT guidelines and developed for use across SE London, by all staff involved in management of end-stage heart failure.

Acknowledgement & thanks are given to Dr Teresa Beynon (Consultant in Palliative Care & author of the Guy’s & St Thomas’ NHS Foundation Trust Guidelines for Symptom Control & Palliative Care Referral for Adult Patients with End-Stage Heart Failure), for allowing the adaptation of those guidelines for use in SE London. With thanks also to Working Group members, and the Guy’s & St Thomas’ Charity.

2. Definition of palliative care

An approach that aims to improve the quality of life of patients and their families facing the problems associated with life threatening illness.

The aim of palliative care is to prevent and relieve suffering where possible through early intervention and impeccable assessment and treatment of pain and other problems - physical, psychosocial and spiritual (World Health Organisation 2002)

3. Specialist Palliative care referral criteria and process

The referral criteria and process is outlined in Appendix III

There is a SE London Specialist Palliative care referral form, that can be accessed via the SE London Cancer Network website at www.selcn.nhs.uk or would be available from your local Specialist Palliative Care team (see Appendix V for contact details).

You may wish to discuss a patient with a member of the relevant Specialist Palliative Care Team.

For community based patients, it is likely to be in the patient’s best interests to cease hospital based review by the cardiac team as they become frailer and their prognosis shorter. As with heart failure teams, Specialist Palliative Care Teams can review patients in all settings.
4. A guide to symptom control

General advice

Continue symptom control alongside optimised active cardiological management - as long as these medications remain appropriate. Optimum palliation of the symptoms of heart failure often depends on patient compliance with medication, especially diuretics.

The SE London Cancer Network’s ‘Adult and Paediatric Palliative Care Guidance’ (2nd edition) may be a useful resource and is available via their website at www.selondon.nhs.uk

Consider physical and psychological aspects of the patient’s life.

Consider whether there are particular issues worrying or frightening the patient. It can be helpful to explore the meaning of a symptom with a patient e.g. if pain or breathlessness worsens, do they assume ‘I am getting worse’

The multidisciplinary team; should other members be involved? e.g. physiotherapist, clinical pharmacist, occupational therapist, social worker, psychologist, chaplain. Adjustments in lifestyle or expectations may be needed.

Look for treatable precipitants of symptoms if the patient deteriorates e.g. non-compliance with medication, chest infection, anaemia, thyrotoxicosis, recent myocardial infarct, arrhythmia.

In all cases where further advice is needed please contact the relevant Specialist Palliative Care Team

Breathlessness

Consider possible causes of breathlessness other than heart failure

Psychological causes (e.g. anxiety)

Concomitant medical problems (e.g. chest infection, COPD, anaemia)

Treat as appropriate.

Pharmacological management of breathlessness due to heart failure

Consider escalating heart failure medication

Ask for a review by the Heart Failure Team (see Appendix IV: Local Heart Failure Teams)

Oramorph® oral solution (morphine sulphate 10 mg/5 mL)¹
Starting dose 2.5 mg 4-hourly.

Titrate the dose every 48 hours according to effectiveness and tolerance.

For patients already on a strong opioid contact the relevant Specialist Palliative Care Team for advice.

Humidified oxygen

High flow humidified oxygen unless evidence of COPD or CO2 retention.

Humidified oxygen at home only available at flow rate > 3 L/min (i.e. FiO2 via Venturi face mask at 4 L/min).

Humidifying oxygen is sometimes not possible when administered via nasal specula but it may still be helpful to consider these, particularly if the person is feeling claustrophobic with the use of a Venturi face mask.

Anxiolytics

Though potentially helpful, their use - particularly when used long-term - will require careful monitoring due to risk of sedation. Referral to the Specialist Palliative Care team is recommended.

Lorazepam 0.5 – 1 mg tablets given sublingually (PRN to a maximum dose of 4 mg per day) (unlicensed route of administration), or

Diazepam 2 mg orally at night (starting dose and escalate to 3 times a day according to response).

Buspirone 5 mg orally 2 – 3 times daily (starting dose, escalate according to response every 2 – 3 days; usual range 15 – 30 mg daily in divided doses) may be helpful as second-line treatment where the benzodiazepine has not helped or there are unacceptable side effects e.g. sedation. Buspirone takes longer (up to 2 weeks) to have an effect so is not suitable for emergency use.

Non-pharmacological management of breathlessness due to heart failure

Dyspnoea management

Is training in breathing control appropriate?

Alternative positions to ease breathlessness may be helpful

Occupational therapy – lifestyle adjustments

Psychological support – appreciating impact on lifestyle

Anxiety management and education regarding management of panic attacks

Relaxation
Complementary therapies
Fan, with airflow directed at the patient’s face
Involves community matrons

Cough
Cough may be due to
underlying heart failure (usually)
ACE inhibitors*
another cause e.g. lower respiratory tract infection.

*ACE inhibitors 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 discontinued, substitute with an Angiotensin-II receptor blocker (ARB) such as Candesartan. Review by or discussion with a cardiologist / heart failure specialist team is recommended.

Cough suppressants
Codeine linctus 5 – 10 mL PRN up to 4 times daily.
Oramorph® oral solution (morphine sulphate 10mg/5mL) 2.5 – 5 mg 4-hourly or PRN. (unlicensed indication)
Cough suppressants will generally not be effective in an ACE inhibitor-induced cough.

Difficulty expectorating
Normal saline (sodium chloride 0.9%) 2.5 mL nebulised PRN. (unlicensed indication) may help to loosen tenacious mucus and aid expectoration

Pain
Up to 80% of patients with heart failure experience pain

Managing pain
Assess pain
Take a pain history including
- e.g. site, intensity, aggravating and relieving factors, radiation, interference with activity.
- It may be appropriate to investigate further e.g. with x-ray. Consider this in the context of the patient.

In this group of patients pain is most likely to be non-specific generalised pain from oedema and disuse or may be musculoskeletal. It may be of cardiac origin in which case anti-anginal medication should be considered.

Pain may be affected by other factors therefore consider:
Psychological e.g. low mood, anxiety, meaning of disease progression.
Spiritual e.g. worries about dying, unresolved guilt.

Include other team members where appropriate
- e.g. physiotherapy, pharmacist, occupational therapy, district nurse, social worker, psychologist, chaplain.

Manage pain
Use the Analgesic Ladder as a guide
Prescribe medication:
Orally
Regularly

The Analgesic Ladder

STEP 1
Paracetamol
+/- co-analgesics

STEP 2
Weak opioids
e.g. Codeine
+/- co-analgesics

STEP 3
Strong opioids
e.g. Morphine
+/- co-analgesics

NSAIDs can lead to increased fluid retention and worsening of heart failure so are unlikely to be appropriate in the majority of patients being treated within these guidelines. Where no alternative is thought to be possible, the risk / benefit ratio should be discussed with the patient. If the patient is already well established on, or you are considering starting a NSAID as a co-analgesic in the above analgesic ladder, always seek further advice from the Specialist Palliative Care Team.
Morphine (Step 3 of the Analgesic Ladder)
Starting dose 5 – 10 mg orally 4-hourly

Available preparations
Oramorph® oral solution
(morphine sulphate 10 mg / 5 mL)
Sevredol® tablets
(morphine sulphate 10 mg, 20 mg, 50 mg)

Both short acting immediate release preparations

Morphine undergoes renal excretion
In general, morphine should be avoided in patients with eGFR < 30mL/min or creatinine > 150 micromol/L where by an alternative opioid should be used.

Patients with eGFR 30 – 60mL/min should be monitored closely. In these patients the frequency of morphine may need to be reduced, or an alternative opioid be considered to prevent toxicity. Always consider referral to the Specialist Palliative Care Team for advice.

Consider prophylactic laxatives when commencing weak or strong opioids.

Sensitivity or allergy to Morphine.
Alternative opioids may be more suitable. Advice regarding these can be obtained via referral to the Specialist Palliative Care Team.

Consider whether continued use of paracetamol is required. It may be useful for pain caused by musculoskeletal disease.

Nausea and vomiting
Patients with advanced heart failure may have multiple causes of nausea and vomiting.
Consider measurement of U&E’s and calcium levels.

Common causes of nausea and vomiting in heart failure
✦ May be due to worsening heart failure – consider escalating heart failure medication in consultation with the heart failure team

✦ Discontinue medication that may be worsening nausea or vomiting if possible.

✦ Treat constipation, initially with Senna 2 tablets at night.

For further information on anti-emetics consider contacting the relevant doctor or Specialist Palliative Care Team.

Consider the subcutaneous (or, if in hospital, intravenous route) for patients in whom vomiting is frequent or continuous.

For use of syringe drivers see the SE London Cancer Network Syringe-driver Policy which is available via their website at www.selondon.nhs.uk

Recommended anti-emetics

<table>
<thead>
<tr>
<th>Cause</th>
<th>Antiemetic</th>
<th>Dose and route</th>
</tr>
</thead>
<tbody>
<tr>
<td>Opioids</td>
<td>Haloperidol (unlicensed indication)</td>
<td>1.5 – 3 mg PO/SC at night</td>
</tr>
<tr>
<td>Renal impairment</td>
<td>Haloperidol (unlicensed indication)</td>
<td>1.5 – 3 mg PO/SC at night</td>
</tr>
<tr>
<td>Gastric stasis from opioids, ascites, hepatomegaly</td>
<td>Metoclopramide</td>
<td>10 mg PO/SC 3 times daily</td>
</tr>
<tr>
<td>Unknown cause/intractable vomiting</td>
<td>Ondansetron …may be considered though there is a high risk of constipation with use. Specialist Palliative Care referral advice is recommended before commencing &amp; if intractable vomiting has occurred</td>
<td>8 mg SC twice daily</td>
</tr>
</tbody>
</table>
Cachexia and anorexia

Cardiac cachexia

Many people with heart failure may lose their appetite and find eating difficult. They may tire when eating due to breathlessness. This may lead to significant wasting which may be difficult to spot due to oedema which can mask loss of lean body mass.

Maintaining nutritional intake is important as it can help to maintain function, mobility and help to prevent infections.

All patients should have their nutritional status assessed, which might include use of a recognised nutritional assessment tool, and then be referred to a dietician as indicated.

Suggestions

- Eat little and often. Variety of foods that the patient enjoys.
- Eat 3 small meals and 2-3 snacks including a nourishing drink each day.
- Nutritional supplement drinks can be helpful. These can be obtained via dietetic departments for inpatients or on prescription from the GP for outpatients.
- Review medication and discontinue any for which there is not immediate gain.
- Consider occupational therapy referral for guidance on how to conserve the patient’s energy by alterations in lifestyle.
- Meals on wheels (or a similar resource via social services referral) may be helpful.

Constipation

Cause

One or more of the following

- reduced intake of fluids and food
- diuretics
- immobility
- weak or strong opioids (consider prophylactic laxatives when commencing a strong opioid)

Managing constipation

Stool softener
e.g. Sodium docusate 100 – 500 mg daily in 2 – 3 divided doses

Stimulant laxative
e.g. Senna 2 tablets or 10 mL of liquid once or twice daily

Combination
e.g. Co-danthramer 25/200 (danthron 25 mg, polaxamer ‘188’ 200 mg)
2 caps once or twice daily or 10 mL suspension once or twice daily.

Introduce cautiously if the patient is incontinent of urine and/or faeces, as danthron may cause skin escoriation.

Osmotic
e.g. Movicol® oral powder 1 – 3 sachets daily in divided doses.
For use in faecal impaction contact the Specialist Palliative Care Team.

Peripheral oedema

This may include arms and genitalia as well as lower limbs.

Management

- Diuretics
  Consider an intravenous infusion of a suitable diuretic or oral Metolazone
  Ensure fluid intake not excessive
- Skin care
  Dry skin may be helped by Aqueous cream in the first instance. For alternatives contact the Specialist Palliative Care Team
  Pruritus may be helped by a mixture of Aqueous cream + 0.5% menthol
- Elevation of the legs may reduce peripheral oedema and aid comfort
  Compression bandaging is generally not recommended as it can cause skin damage due to inappropriately applied pressure and may increase venous return, thereby stressing an already overloaded organ
  If there is lymphorrhoea (skin breaks due to leakage of fluid) the limb may benefit from gentle bandaging using retention bandages or tubinette
  Advice from Tissue Viability, Lymphoedema and/or District nurses may be helpful in these circumstances.
Consider referral to occupational therapy or counsellor for relaxation / stress management or cognitive behavioural therapy. For some patients, referral to a psychologist or a psychiatrist may be required.

With severe emotional distress AND / or physical symptoms, ensure community heart failure nurse is involved +/- Specialist Palliative Care Team.

Massage and aromatherapy can be helpful in reducing anxiety & depression. Consider referral to complementary therapy service.

Pharmacological Management

Antidepressants
Sertraline 50 mg daily
- recommended for generalised anxiety disorder
Mirtazepine 15 – 30 mg at night
- useful if associated nausea or poor appetite
- sedative so aids sleep and reduces anxiety

Cautions
- Avoid tricyclic antidepressants in view of cardiotoxic side-effects.
- Do not stop/change established antidepressants if not causing obvious harm.

Night sedation
Temazepam 10 – 20 mg at night

Anxiolytics
Though potentially helpful, their use – particularly when used long-term- will require carefully monitoring due to risk of sedation. **Referral to the Specialist Palliative Care team is recommended.**

Lorazepam 0.5 – 1 mg tablets given sublingually especially for panic attacks (PRN to a maximum dose of 4mg per day) (Unlicensed route of administration) or
Diazepam 2mg orally at night for anxiety (starting dose and escalate to 3 times a day according to response).

Scrotal supports for scrotal oedema may be helpful. It is important the correct size is ordered to avoid skin damage. Contact your local Surgical Appliances service.

Review expectations of patient and carer.

Consider the possibility that additional support that might be required at home.

Dry mouth
Assess for any underlying cause e.g. oxygen, medication, oral thrush

Management
Treat and reverse underlying cause if possible. Consider nasal speculae or humidification if dryness caused by oxygen.

Discontinue medication if possible.

May be helped by one or more of the following:
- Sucking on ice cubes
- Sipping pineapple juice
- Chewing sugar-free gum (requires residual salivary function)
- Oralbalance® (Biotene Oralbalance) gel

Psychological issues
Non-Pharmacological Management
- Explore any concerns and deal with these if possible.
- Ask about sleep – general anxiety or death phobias are often worse at night.
- Ask about mood.
- Investigate current support networks e.g. friends / family, religious organisations.

Consider referral to occupational therapy or counsellor for relaxation / stress management or cognitive behavioural therapy. For some patients, referral to a psychologist or a psychiatrist may be required.

With severe emotional distress AND / or physical symptoms, ensure community heart failure nurse is involved +/- Specialist Palliative Care Team.

Massage and aromatherapy can be helpful in reducing anxiety & depression. Consider referral to complementary therapy service.

Pharmacological Management

Antidepressants
Sertraline 50 mg daily
- recommended for generalised anxiety disorder
Mirtazepine 15 – 30 mg at night
- useful if associated nausea or poor appetite
- sedative so aids sleep and reduces anxiety

Cautions
- Avoid tricyclic antidepressants in view of cardiotoxic side-effects.
- Do not stop/change established antidepressants if not causing obvious harm.

Night sedation
Temazepam 10 – 20 mg at night

Anxiolytics
Though potentially helpful, their use – particularly when used long-term- will require carefully monitoring due to risk of sedation. **Referral to the Specialist Palliative Care team is recommended.**

Lorazepam 0.5 – 1 mg tablets given sublingually especially for panic attacks (PRN to a maximum dose of 4mg per day) (Unlicensed route of administration) or
Diazepam 2mg orally at night for anxiety (starting dose and escalate to 3 times a day according to response).
Many patients with confirmed heart failure (40-50% in some studies) will experience sudden cardiac death. Others will deteriorate more slowly.

Consider where the patient wants to be cared for and to die; through sensitive discussion with them +/- their relevant family members / carers. A care package may be needed involving assessment by the occupational therapist, physiotherapist and social worker (+/- access to ‘continuing care’ funding) to support the person remaining in their preferred place of care.

Diagnosing ‘dying’ in heart failure
It can be more difficult to diagnose dying in heart failure than in many terminal cancer patients and to define when they are in a palliative phase.

The Liverpool Care Pathway for the Dying (LCP)
Enables a multidisciplinary discussion to diagnose that the patient is dying.

The LCP encourages:

1. Review of medication
   Are all medications necessary? Continue those providing symptomatic benefit.
   - Does route of administration need to be reviewed? e.g. should medication be given subcutaneously? Is a syringe driver required?
   - Review and discontinuation of inappropriate interventions e.g. venepuncture, regular TPR measurement, intravenous fluids.

2. Review of Cardiopulmonary Resuscitation status
   - Implantable cardioverter defibrillators (ICD) and pacemakers
     Requires consultant led discussion with patient and family regarding when would be an appropriate time to switch this off. The cardiac technicians will need to deactivate the device or magnets used.
     - Similarly, if they have an epidural implant it is important to consider when it would be appropriate to stop topping this up.

Overall it enables
- Regular assessment of symptoms and adjustment of medications if symptoms not adequately controlled.
- Psychological support of patient and family.
- Good, clear but sensitive communication.
- Spiritual care according to patient’s cultural and religious beliefs.

For prescribing advice in end-of-life care, contact the relevant local Specialist Palliative Care Team.

5. The last few days of life

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

Patients may improve with review of medication, or other changes in their treatment e.g. pacemaker.

If recovery is uncertain or the patient is considered to be imminently dying this should be shared with the family.

If the patient is felt to be imminently dying a discussion should take place within the team about the patient’s condition and a decision agreed regarding whether the patient should be entered on to the Liverpool care pathway for the dying (as available).
6. Financial benefits

Disability Living Allowance (DLA) and attendance allowance (AA)
(DLA under 65 years; AA 65 years or older)

To qualify the patient must:
(i) need help getting around
(ii) need help with personal care
(iii) both (i) and (ii)
(iv) usually be disabled for at least 6 months to qualify

Special Rules for DLA and AA
Patients with an estimated prognosis of less than 6 months can claim Disability Living Allowance or Attendance Allowance under the “Special Rules”. There is a higher rate paid & they do not have to satisfy the usual disability tests or serve the relevant qualifying periods. A doctor needs to complete a DS1500 form to verify the patient’s condition.

Disabled parking badges
The ‘blue badge’ scheme provides patients with parking benefits within the UK and Europe. Patients are entitled to this if they receive the higher rate of the mobility component of the DLA or War Pensioner’s Mobility supplement or if they have a substantial disability which causes inability or considerable difficulty in walking.

Prescription charges
Patients are eligible for free prescriptions if they are able to leave the house only with the help of another person. A ‘prescription exemption’ form is available at local pharmacies. An exemption card will be issued upon successful application

Travel insurance
Travel abroad should only be considered with full insurance for patients with end-stage heart failure. Difficulty may be encountered when seeking this.

Carers allowance
This is a benefit for people who care for someone who is disabled. The carer does not have to be related or live with the person they care for but must be 16 or over and spend at least 35 hours a week caring for a person in receipt of DLA (middle or higher rate) or AA.

NHS Continuing Care Funding
The Department of Health’s ‘National Framework for NHS Continuing Healthcare and NHS-funded nursing care’ (2007) has allowed those patient’s with a high level of nursing needs to have a home care package that is fully NHS funded.

Applications to the relevant Primary Care Trust for consideration of such funding should be made using the appropriate form.

In situations where the patient’s condition deteriorates suddenly, death may be imminent, and care plus funding is required quickly, a ‘Fast Track Pathway tool’ is available.

7. Useful links

Travel insurance
BACUP
08088 001 234
www.cancerbacup.org.uk

British Heart Foundation
020 7935 0185
www.bhf.org.uk

Hospice information service
0870 903 3 903
www.hospiceinformation.info

Finances
Citizens Advice Bureau
020 7833 2181
www.adviceguide.org.uk

Disability Benefits Helpline
08457 123 456
www.disabilitybenefits.co.uk
Appendix 1

Reference List

(8) Ellershaw J, Ward C. Care of the dying patient: the last hours or days of life. BMJ 2003; 326(7379):30-34.
Appendix II

Contributors

Working Group Members For The GSTTFT Guidelines

Helen Alexander  Physiotherapist
Marsha Atomon  Clinical Nurse Specialist, Palliative Care
Azizah Attard  Senior Psychiatric Liaison Pharmacist
Dr. Teresa Beynon  Consultant In Palliative Medicine
Dr. Irene Carey  Consultant Palliative Medicine
Dr. Gerry Carr-White  Consultant Cardiologist
Elaine Coady  Consultant Nurse Cardiology
Jane Collier  Occupational Therapy
Teresa Day  Dietician
David Hamilton  Clinical Nurse Specialists, Palliative Care
Richard Harding  Lecturer, Department Of Palliative Care And Policy
Professor Irene Higginson  Professor Of Palliative Medicine
Fiona Hodson  Clinical Nurse Specialist, Heart Failure
Duncan Mcrobbie  Principal Pharmacist, Clinical Services
Dr. Vivienne Mak  Lead LCP Facilitator
Caroline Read  Clinical Nurse Specialist, Heart Failure
Lucy Selman  Research Associate
Paul Sigel  Clinical Psychologist, Cardiology
Steven Wanklyn  Senior Pharmacist, Palliative Medicine

Adapted into Network document by:

Mary O’Sullivan  Senior Project Manager, SE London Cardiac & Stroke Network
Kath McDonnell  Palliative & End-of-Life Care Programme Manager, SE London Cancer Network

In conjunction with the SELCN Palliative & End of Life Policy Group, the SE London Palliative & End of Life Care Coordinating Group members, and the South East London Cardiac and Stroke Network Heart Failure Work stream group.

Key contacts

Mary O’Sullivan  Senior Project Manager, Heart Failure
SE London Cardiac & Stroke Network
Tel: 020 8768 4960
Email: Mary.O’Sullivan@lewishampct.nhs.uk

Kath McDonnell  Palliative & End of Life Care Programme Manager
SE London Cancer Network
Tel: 020 7188 2088
Email: Kath.McDonnell@gstt.nhs.uk

Appendix III

Referral pathway for specialist palliative care for patients with end stage heart failure

South East London Cardiac Network / South East London Cancer Network

[Diagram of referral pathway]

Patient meets Criteria for Referral*
If URGENT contact Specialist Palliative Care Team Directly
Criteria for Referral

All cardiac patients being referred to the palliative care team MUST

a. Have been reviewed by the heart failure team
b. Know they have a diagnosis of heart failure
c. Agree to the referral, both patient and medical team

Routine referrals will be contacted within 2 working days to arrange an assessment. For urgent referrals, direct contact with the palliative care team is needed to discuss each situation individually.

Criteria for Urgent Referral needing advice/assessment within 1-2 working days.

- Difficult psychological/physical symptoms causing distress and not responding to current management
- Rapidly deteriorating condition

Referral is recommended if one or more of the following apply:

1. Symptomatic (e.g. breathless at rest or minimal exertion) despite optimal treatment.
2. Heart failure patients when hospital admission may not be the best/only/preferred option, or for whom palliative care (hospice, day care, hospital inpatient or community care) may be of benefit, either immediately or in the future.
3. Optimal therapy but continuing or deteriorating physical and/or psychological symptoms. Where only psychological issues are present consider referral to clinical psychology.
4. Where the family or carer(s) would benefit from support, either immediately or in the future (including bereavement).
5. Where the patient has had two or more previous admissions for heart failure within the last six months.

Referral process

Please RING AND DISCUSS if you are uncertain whether referral is appropriate.

The following should have already taken place:

- Open discussion with both patient and family/carers (this can be challenging; if difficulties are encountered these should be discussed with palliative care so that the process can be facilitated)
- First line management for identified symptom problems, as per established guidelines

Specialist palliative care input may come in a number of ways:

1. Telephone advice for specific symptom management problems for healthcare professionals in the hospital or community setting.
2. One off assessment from specialist palliative care at home with follow up by generic primary care services. +/- Heart failure services.
3. One off assessment/input in the secondary setting, either on the wards, or in out-patients with follow-up predominantly by heart failure services.
4. Ongoing support from community palliative care services (regular home visiting), with all other hospice services available. This would be for patients who have particularly complex or multiple symptoms (physical, psychological, social, or spiritual), and when a mutual decision has been taken against active, interventional treatment.
5. Continuing support form hospital palliative care services whilst the patient remains an inpatient, with ongoing specialist palliative care referral when discharged to another setting, e.g. home or hospice if referral appropriate.

Any Health Care Professional can refer to the Specialist Palliative Care Team, but acceptance must be with the agreement of the GP/inpatient Consultant.

Where possible, the patient, and if not, the carer, should be informed and in agreement with the referral.

Patients may be discharged if their condition stabilises.

Contacts:

- The heart failure teams (see Appendix IV. Local Heart Failure Teams).
- Details of all SE London specialist palliative care providers are in Appendix V
## Appendix IV

### Contact Details for Heart Failure Service

SE London Sector July 2009

<table>
<thead>
<tr>
<th>Hospital HF Service</th>
<th>Community HF Service</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Bexley</strong></td>
<td></td>
</tr>
<tr>
<td>Dr Brian Gould – Consultant Cardiologist</td>
<td>Kathy Gore – Locality Nurse Lead</td>
</tr>
<tr>
<td><a href="mailto:brian.gould@nhs.net">brian.gould@nhs.net</a></td>
<td><a href="mailto:kathy.gore@bexley.nhs.uk">kathy.gore@bexley.nhs.uk</a></td>
</tr>
<tr>
<td>Eileen Vandervennin – Heart Failure Nurse Specialist (HFNS)</td>
<td>Achyut Dhitia – HF GP (Via PA)</td>
</tr>
<tr>
<td><a href="mailto:eileen.vandervennin@nhs.net">eileen.vandervennin@nhs.net</a></td>
<td><a href="mailto:s.taylor5@nhs.net">s.taylor5@nhs.net</a></td>
</tr>
<tr>
<td><strong>Bromley</strong></td>
<td></td>
</tr>
<tr>
<td>Dr Stefan Karwatowski – Consultant Cardiologist</td>
<td>Caroline Mapstone - BHF HFNS</td>
</tr>
<tr>
<td><a href="mailto:stefan.karwatowski@nhs.net">stefan.karwatowski@nhs.net</a></td>
<td><a href="mailto:caroline.mapstone@bromleypct.nhs.uk">caroline.mapstone@bromleypct.nhs.uk</a></td>
</tr>
<tr>
<td>Andrew Taylor – HFNS</td>
<td>Ray Upchurch – HFNS</td>
</tr>
<tr>
<td><a href="mailto:andrew.taylor@nhs.net">andrew.taylor@nhs.net</a></td>
<td><a href="mailto:ray.upchurch@bromleypct.nhs.uk">ray.upchurch@bromleypct.nhs.uk</a></td>
</tr>
<tr>
<td><strong>Greenwich</strong></td>
<td></td>
</tr>
<tr>
<td>Sue Simpson – Nurse Consultant</td>
<td>Mary Nash - Cardiac Community Matron</td>
</tr>
<tr>
<td><a href="mailto:sue.simpson@nhs.net">sue.simpson@nhs.net</a></td>
<td><a href="mailto:mary.nash@nhs.net">mary.nash@nhs.net</a></td>
</tr>
<tr>
<td>Peta Rudd – HFNS</td>
<td>Carol Severs – Cardiac Community Matron</td>
</tr>
<tr>
<td><a href="mailto:p.rudd@nhs.net">p.rudd@nhs.net</a></td>
<td><a href="mailto:carol.severs@nhs.net">carol.severs@nhs.net</a></td>
</tr>
<tr>
<td><strong>Lambeth</strong></td>
<td></td>
</tr>
<tr>
<td>Dr Gerry Carr-White – Cardiology Consultant</td>
<td>Amanda Parsons – BHF HF Nurse Specialist</td>
</tr>
<tr>
<td><a href="mailto:gerry.carr-white@gstt.nhs.uk">gerry.carr-white@gstt.nhs.uk</a></td>
<td><a href="mailto:amanda.parsons@lambethpct.nhs.uk">amanda.parsons@lambethpct.nhs.uk</a></td>
</tr>
<tr>
<td>Fiona Hodson – HFNS</td>
<td>Lilly Mandarano – BHF HFNS</td>
</tr>
<tr>
<td><a href="mailto:fiona.hodson@gstt.nhs.uk">fiona.hodson@gstt.nhs.uk</a></td>
<td><a href="mailto:lilly.mandarano@lambethpct.nhs.uk">lilly.mandarano@lambethpct.nhs.uk</a></td>
</tr>
<tr>
<td>Annie O’Donaghue – HFNS</td>
<td>Rebecca Curran – HF Pharmacist</td>
</tr>
<tr>
<td>annie.o'<a href="mailto:donaghue@gstt.nhs.uk">donaghue@gstt.nhs.uk</a></td>
<td><a href="mailto:rebecca.curran@lambethpct.nhs.uk">rebecca.curran@lambethpct.nhs.uk</a></td>
</tr>
<tr>
<td>Caroline Read – HFNS</td>
<td></td>
</tr>
<tr>
<td><a href="mailto:caroline.read@gstt.nhs.uk">caroline.read@gstt.nhs.uk</a></td>
<td></td>
</tr>
<tr>
<td>Ana Felton – HFNS</td>
<td></td>
</tr>
<tr>
<td><a href="mailto:ana.felton@gstt.nhs.uk">ana.felton@gstt.nhs.uk</a></td>
<td></td>
</tr>
<tr>
<td><strong>Lewisham</strong></td>
<td></td>
</tr>
<tr>
<td>Dr Sanjay Sharma – Consultant Cardiologist</td>
<td>Philippa Askew - HFNS</td>
</tr>
<tr>
<td><a href="mailto:sanjay.sharma@kch.nhs.uk">sanjay.sharma@kch.nhs.uk</a></td>
<td><a href="mailto:philippa.askew@lewishampct.nhs.uk">philippa.askew@lewishampct.nhs.uk</a></td>
</tr>
<tr>
<td>Tracy Ronne – HFNS</td>
<td>Ife Okeyode – HFNS</td>
</tr>
<tr>
<td><a href="mailto:tracy.ronne@uhl.nhs.uk">tracy.ronne@uhl.nhs.uk</a></td>
<td><a href="mailto:ife.okeyode@lewishampct.nhs.uk">ife.okeyode@lewishampct.nhs.uk</a></td>
</tr>
<tr>
<td>Ife Okeyode – HFNS</td>
<td>William Nti-Nimako – HFNS</td>
</tr>
<tr>
<td><a href="mailto:ife.okeyode@lewishampct.nhs.uk">ife.okeyode@lewishampct.nhs.uk</a></td>
<td><a href="mailto:william.nti-nimako@lewishampct.nhs.uk">william.nti-nimako@lewishampct.nhs.uk</a></td>
</tr>
<tr>
<td>William Nti-Nimako – HFNS</td>
<td></td>
</tr>
<tr>
<td><a href="mailto:william.nti-nimako@lewishampct.nhs.uk">william.nti-nimako@lewishampct.nhs.uk</a></td>
<td></td>
</tr>
<tr>
<td><strong>Southwark</strong></td>
<td></td>
</tr>
<tr>
<td>Dr Sanjay Sharma – Consultant Cardiologist</td>
<td>Gillian Philip – HFNS</td>
</tr>
<tr>
<td><a href="mailto:sanjay.sharma@kch.nhs.uk">sanjay.sharma@kch.nhs.uk</a></td>
<td><a href="mailto:gillian.philip@southwarkpct.nhs.uk">gillian.philip@southwarkpct.nhs.uk</a></td>
</tr>
<tr>
<td>Julia DeCourcey – HF Nurse Consultant</td>
<td></td>
</tr>
<tr>
<td><a href="mailto:julia.decourcey@nhs.net">julia.decourcey@nhs.net</a></td>
<td></td>
</tr>
<tr>
<td>Clare Chitty – HFNS</td>
<td></td>
</tr>
<tr>
<td><a href="mailto:clare.chitty@nhs.net">clare.chitty@nhs.net</a></td>
<td></td>
</tr>
</tbody>
</table>
# Appendix V

## SE London Specialist Palliative Care teams

Including fax numbers for use in sending patient referrals

1. **Greenwich & Bexley Cottage Hospice**  
   185 Bostall Hill,  
   Abbey Wood,  
   London, SE2 0GB  
   Tel: 020 8312 2244  
   Fax: 020 8312 4344 (for general referral forms)  
   www.cottagehospice.org.uk

   Greenwich & Bexley Cottage Hospice Outreach Services:  
   a. **Greenwich Community Palliative Care Team**  
      Tel: 8836 5432  
      Fax: 8836 5952
   b. **Queen Elizabeth Hospital Palliative Care Team**  
      Tel: 8836 5442  
      Fax: 8836 5428

2. **Ellenor Lions Hospices**  
   The Ellenor Centre  
   St Ronans View,  
   East Hill Drive, Dartford  
   Kent, DA1 1AE  
   Tel: 01322 221315  
   Fax: 01322 626503  
   www.ellenorfoundation.org

   North Bexley community Palliative Care Team:  
   Tel: 8310 4100  
   Fax: 8312 2115

   South Bexley community Palliative Care Team:  
   Tel: 8308 3014  
   Fax: 8308 3168

3. **Queen Mary’s Hospital Palliative Care Team**  
   Queen Mary’s Hospital,  
   Sidcup,  
   Kent, DA14 6LT  
   Tel: 020 8308 3297  
   Fax: 020 8308 3168

4. **Harris Hospiscare with St Christopher’s**  
   Community Palliative Care team  
   Harris HospisCare, Caritas House,  
   Tregony Road, Orpington,  
   Kent, BR6 9XA  
   Tel: 01689 825755  
   Fax: 01689892999  
   www.harrishospiscare.org.uk

5. **Princess Royal University Hospital Palliative Care Team**  
   Princess Royal University Hospital  
   Farnborough Common, Orpington  
   Kent, BR6 8ND  
   Tel: 01689 865667  
   Fax: 01689 864070

6. **St Christopher’s Hospice**  
   51-59 Lawrie Park Road  
   London, SE26 7DZ  
   Inpatient unit  
   Tel: 020 8768 4500  
   Fax: 020 8659 8680  
   St Christopher’s at Home  
   Tel: 8776 5656  
   Fax: 8776 5798  
   www.stchristophers.org.uk

7. **Guy’s & St Thomas’ Hospitals Palliative Care Team**  
   Hospital & Community Palliative Care Teams  
   Guy’s Hospital site:  
   Tel: 7188 4754  
   Fax: 7188 4748  
   St Thomas’ Hospital site:  
   Tel: 020 7188 4755  
   Fax: 020 7188 4720

8. **Trinity Hospice**  
   In patient unit & community palliative care teams  
   30 Clapham Common North Side  
   London, SW4 ORN  
   Tel: 020 7787 1000  
   Fax: 020 7787 1067  
   www.trinityhospice.org.uk

9. **Lewisham Macmillan Support Team**  
   Hospital & community palliative care teams  
   David Whitmore Suite (Suite 8), Lewisham Hospital, SE13 6LH  
   Tel: 8333 3017  
   Fax: 8333 3270

10. **King’s College Hospital Palliative Care Team**  
    King’s College Hospital, Denmark Hill, SE5 9RS  
    Tel: 3299 4060  
    Fax: 3299 4713

---

**Note:**  
For detailed contact information, please refer to the respective websites provided.
Helpful Resources


End of Life Care Strategy, Department of Health. July 2008