Advanced heart failure external guidance

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February 2015	V2 - Diane Laverty – Nurse Consultant in Palliative Care	
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May 2021	V4 Dr Mitali Patel Locum Consultant in Palliative Medicine	
April 2023	Reviewed by Dr Rosalind Haire – ST5 Palliative Medicine and Dr Andrew Tyso-Calnon Minor changes - remove CMC, insert UCP.	May 2023 D&P

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Referral criteria and process into specialist palliative care services at STJH

We advise that all patients being considered for referral to STJH have had a recent review by a heart failure specialist nurse or cardiologist. This will ensure the patient is receiving optimal management for their heart failure, has been considered for device therapy and reversible causes for symptomatic deterioration have been ruled out. See appendix II for details of local heart failure services.

STJH accepts referrals for community, inpatient and outpatients services for people registered with a GP in the boroughs of **Tower Hamlets, Newham and City and Hackney**. The inpatient services are also available to those registered with a GP within the other boroughs of NHS North East London and all of NHS North Central.

You may speak to a member of the First Contact team by calling **0300 30 30 400** to discuss potential referrals. **For out of hours advice and emergencies please contact St Joseph's main switchboard on 0208 525 6000** and you will be put through to someone who can help you.

Criteria for referral to specialist palliative care

The patient must have a diagnosis of heart failure, symptoms of breathlessness on minimal exertion or rest (NYHA stage 3-4) and is not a candidate for further cardiac interventions. The patient and their medical team (consultant or GP) should be aware of and agree to the referral.

Plus two or more of the following:

The patient:

- ✓ has had multiple episodes of decompensation (fluid overload) during the past 12 months
- ✓ is thought to be in the last year of life
- ✓ has complex physical or psychological symptoms despite optimal tolerated therapy
- ✓ would like to formalise advance care planning options
- ✓ has a preference is to be cared for by STJH, as an alternative to hospital admission.

Specialist palliative care input at St Joseph's is available as follows:

- **Inpatient care** - admission to one of two wards for symptom control, palliative rehabilitation, unplanned respite care and/ or terminal care.
- **Community palliative care team -** referral is made to a borough specific team consisting of clinical nurse specialists. Additional support of specialist palliative care doctors, therapists and social workers are available if necessary.
  The referrer may be offered a joint assessment with the Palliative Care nurse depending on the individual patient's needs. Patients may be discharged from the community services if their condition stabilizes. Re-referral can be made directly via telephone by the patient or professional if it is within 6 months of discharge.
- **Outpatient services** - such as day hospice, psychology, social work, bereavement, breathlessness management, occupational therapy, physiotherapy and complementary therapy**.**

- **Dedicated Respite service -** set weeks of respite are available to patients who are medically stable and would benefit from a break from their usual care setting. Referrals can be made via the First Contact team.

What to expect post referral

All referrals go directly to the First Contact team at St Joseph's. Each person referred will be contacted within two working days and assessed on an individual basis as to the suitability of our services. Detailed information must be included (**e.g. clinical letters and investigations**) with the referral to help the triage team build the clinical picture. Once the referral has been triaged, the case will then be passed on to the relevant team and the patient will be seen within 1-10 working days, depending on their clinical priority. If the referral is thought to be inappropriate the referrer will be contacted. **At weekends contact will only be made with patients in an emergency situation.**

Patients referred for admission to the hospice will be offered a bed within 3 working days of the receipt of the referral and accompanying information, if the referral is thought to be appropriate and a bed is available. In the event that there is a delay, the referrer will be notified.

Patients referred to the Community Palliative Care Team will be assessed and the outcome will be communicated to the referrer within 2 working days of the assessment.

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

Please follow up all urgent referrals with a call to the First Contact team on: 0300 30 30 400

Gold Standards Framework

The Gold Standards Framework (GSF) is an approach to providing optimal care for patients nearing the end of their lives.

If a person with heart failure is being considered for referral to palliative care services, it may be appropriate that their name is placed on the GSF register held by their GP. This helps aid communication and coordination amongst professionals involved in the person's care.

In addition, all advanced heart failure patients should be considered for inclusion on the Universal Care Plan for London (UCP) programme. This is a clinical service which shares information between healthcare professionals about the patient's wishes for their future care.

Financial & Welfare Rights Advice

People with heart failure, and their carers may be entitled to the financial benefits listed below

- Disability Living Allowance (DLA) and Attendance Allowance (AA)
- Special Rules (for those with short prognosis) for DLA and AA
- Disabled parking badges
- Exemption from Prescription charges
- Carers allowance
- NHS Continuing Care Funding ('*Fast Track*' is considered for those with a short prognosis).

For signposting patients or more information please contact:

- *Citizens Advice Bureau*
  0800 1448848
  www.citizensadvice.org.uk

- *Advice Local*
  - benefits advice, money, work, housing problems

  https://advicelocal.uk/

- *Disability Benefits Helpline*
  08457 123 456
  www.disabilitybenefits.co.uk

Bereavement Support

Ensure bereaved persons are assessed for bereavement risk before and after death. Offer support and guidance about how they might feel during this difficult time. If you have concerns about the person or feel they need more support ensure appropriate referrals are made.
Following bereavement, some people find it difficult to talk about the way they are feeling, especially to family and friends. However, sharing painful feelings with someone who cares can often help. **To access bereavement support at STJH call 0208 525 6031.**

The deceased person does need to have been previously known to STJH.

The British Heart Foundation also has a 'Heart Helpline' and a bereavement support office for relatives to contact if needed. The number is 0300 3303311. This helpline is open 9am-5pm Monday – Friday.

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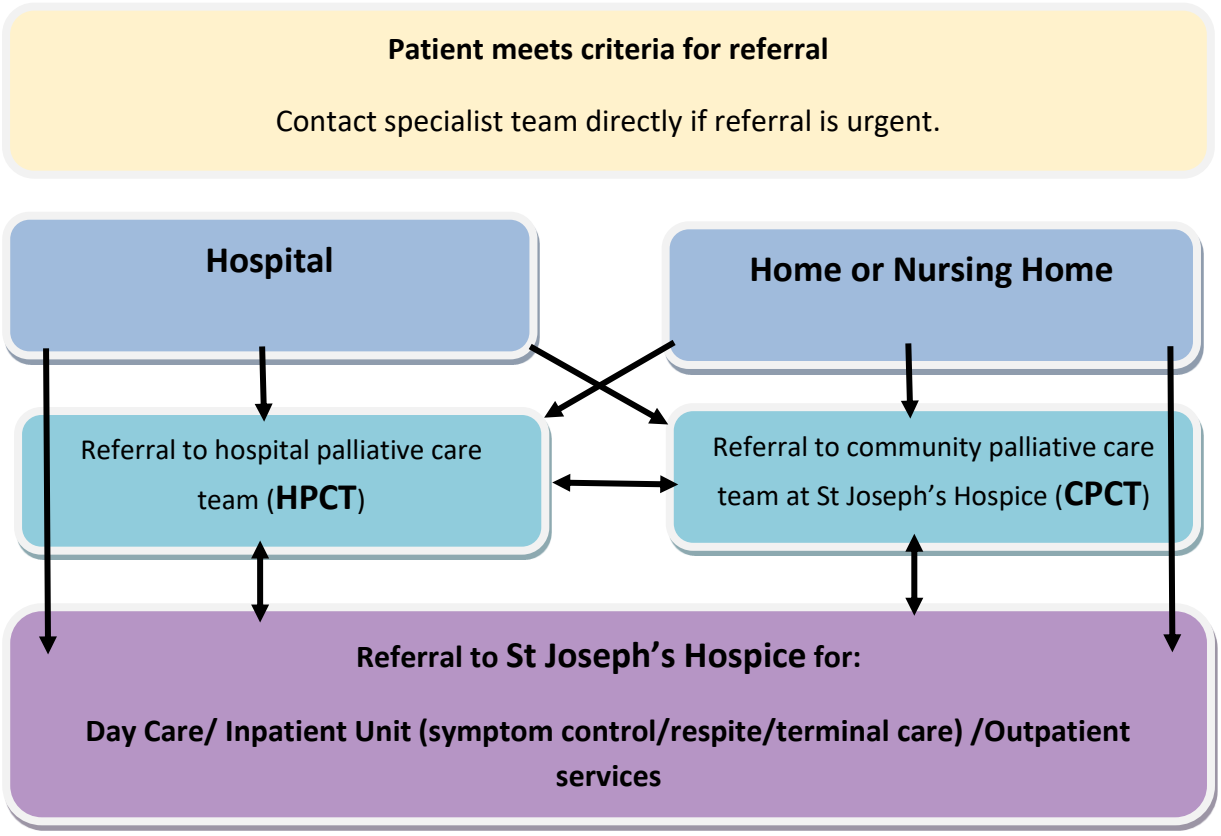
Appendix I: Palliative care pathway



Appendix II: Specialist Palliative Care Providers

For more information on services offered by each provider below please see www.HospiceUK.org.uk.

	Hospital Palliative Care Service	Hospice/ Community Palliative Care Services
Camden	**UCLH & Camden PCT** UCLH, NW1 2PG Phone: 020 7380 6811	**Marie Curie Hospice**, Hampstead. Phone: 020 7853 3400 **Hospital team also cover community** -& St Joseph's Hospice
City & Hackney	**Homerton University College Hospital Foundation NHS Trust,** Phone: 020 8510 7819	**St Joseph's Hospice, Hackney** Phone: 020 8525 6000 FCT: 0300 30 30 40 Community Team: 020 8525 6060
Haringey	**Haringey Palliative Care Team** The Willows, St Ann's Hospital. Phone**:** 020 8442 5544	**North London Hospice**, Barnet Phone: 020 8343 8841 Community phone: 020 8343 8841
Newham	**Macmillan Palliative Care Team** Newham University Hospital, Plaistow. Phone: 02073638105	- St Joseph's Hospice
Tower Hamlets	**Macmillan Palliative Care Team** St Bartholomew's Hospital, City of London. Phone: 02076018500	- St Joseph's Hospice
Waltham Forest	**The Margaret Centre** Whipps Cross University Hospital, Leytonstone. Phone: 020 8535 6604	The Margaret Centre, Whipps Cross University Hopsital & St Joseph's Hospice