Specialist Palliative Care Service Referrals

These guidelines cover referrals for patients with progressive terminal illness, whether due to cancer or any other life limiting diseases.

For many patients in the late stages of their illness, palliative care needs are fairly straightforward and can be met by the Primary Care Team (District Nurse and GP).

However, if there is complex symptom control or psychosocial issues present or predictable, then advice from or involvement with the Specialist Palliative Care service should be considered.

How can you access the advice?

The service operates 7 days per week between 8:30 - 17:00. Referral to the service is via Referral Form available in hard copy. An electronic version is available on our intranet or via the EMIS system.

If you would like advice or further Referral Forms, please contact a member of the team: **Telephone:** 0151 295 3676 - **Fax:** 0151 296 7528

During the weekend and bank holiday periods, two clinical Nurse Specialists cover the Liverpool and South Sefton area. Their contact details are:

**Liverpool:** 07887 568 790 / 07798 808 148 / 07917 598 595  
**South Sefton:** 0791 921 8579

Alternatively, the situation could be discussed with the team at the bi weekly Multi-Disciplinary Team meetings. The meetings are held at the following locations:

- Monday morning - ‘catch up’ meeting with a Consultant in Palliative Medicine
- Wednesday morning - Woodlands Hospice
- Thursday morning - Liverpool Marie Curie Hospice

There are helplines available out of office hours:

**Liverpool Marie Curie Hospice:** 0845 223 2900  
**Woodlands Hospice:** 0151 529 3674

Advice

The service can provide advice on the use of a particular drug or service, or a wider discussion of patient’s current and predicted situations. We can explore if any further treatment or other service may be available to the team caring for them with regards to symptom control and potential actions.
Assessment

An initial holistic assessment of the patient can be facilitated by a member of the Specialist Palliative Care Nursing Service, District Nurse and potentially Specialist Palliative Care Consultant. The assessment may be required for advice on a specific aspect of care – e.g. a review of symptom control by the Nurse Specialist, to aid discussion about the direction of care and provide on-going review dependant on clinical need.

Once the patient has been discharged a request for assessment may be repeated as and when new situations arise. This is by referral to the Specialist Palliative Care Service, or following discussion as above.

General referral criteria for the Community Specialist Palliative Care Service

Palliative Care is shared with the Primary Care team and/or Specialist team. The District Nurse is the key worker, and will inform our service of the need for our involvement. Involvement may be for the duration of a particular problem or on-going until death and bereavement.

All of the below

Progressive incurable disease or the patient has declined active treatment if competent to do so.

• Prognosis is less than a year (but see additional groups below)
• There is complex symptom control or psychosocial issues important to the patient that cannot readily be managed by the team responsible for care.
• The patient agrees to referral to the Palliative Care Service if competent to choose.

Additional Groups – may be referred and discussed individually with members of the team as to appropriateness of the referral.

• Some patients who have progressive terminal disease with a longer prognosis than one year, but have complex needs
• Some patients needing support around the time of diagnosis of incurable disease, where a Clinical Nurse Specialist is not available

The focus of Palliative Care is on patients with a prognosis less than a year. However, if practitioners are unsure who to refer they can contact members of the team who will be happy to discuss such patients.
Referrals that would not be considered

- Patients with chronic stable disease, or disability with a life expectancy of several years
- Patients with chronic pain problems not associated with progressive terminal disease
- Competent patients who decline referral or who are unaware of referral
- Patients whose needs are principally psychological, and need specialist psychiatric referral, whether or not they have declined such help

Prognostic Indicators:

The following is intended to provide guidance for professionals looking after patients who may be appropriately referred to the Specialist Palliative Care Service. It is, of course, not exclusive and, as stated above, the team are happy to advise in uncertain situations.

Indicators that referral to the Specialist Palliative Care Service may be appropriate:-

General Indicators

At least one of:
- Progressive deterioration in performance scale (e.g. WHO or Karnofsky – Appendices 1 and 2)
- Dependence in three or more activities of daily living
- Multiple co-morbidities
- Symptoms that cannot be alleviated by treating underlying disease
- Signs of malnutrition due to illness – cachexia; albumin <25g/l
- Severe progression of illness over recent months.

Disease Specific Indicators Suggesting that Referral may help the patient or family/carers.

Cancer
- Incurable metastatic disease or inoperable disease
- Complex symptomatic or psychosocial problems

Cardiac Disease

At least one of:
- Advanced heart failure (New York Heart Association Grade ¾ - see appendix 3)
- 3 or more admissions to hospital within the last 12 months with symptoms of heart failure
- Physical or psychological symptoms despite optimal tolerated therapy
- Symptomatic arrhythmias resistant to treatment
- Physical damage (e.g. stroke) following resuscitation for cardiac arrest and the patient does not want cardiopulmonary resuscitation in the event of a cardiac arrest.
Pulmonary Disease

At least one of:

• Shortness of breath at rest (MRC grade 4 – see Appendix 3)
• Documented progressive disease
• Symptomatic right heart failure
• Cachexia

Renal Disease

Not able or willing to undergo dialysis or transplant and at least one of:

• Patient wishes to stop dialysis
• Signs of renal failure (severe nausea, pruritus, restlessness, altered consciousness)
• Intractable fluid overload
• Rapid deterioration anticipated by renal team

Neurological Disease

• Significant progressive decline in function and at least one of the following:

Inability to walk

• Dependence on assistance with activities of daily living
• Barely intelligible speech; difficulty in communication
• Cachexia; difficulty eating and drinking and declines feeding tube
• Significant dyspnoea and/or requires oxygen at rest and declines assisted ventilation

Stroke

• Persistent vegetative state
• Severe dysphagia
• Post stroke dementia
• Poor nutritional status

Liver Disease

• Ascites despite maximum diuretics; spontaneous peritonitis
• Jaundice; hepatorenal syndrome
• PTT > 5 seconds above control
• Encephalopathy
• Recurrent variceal bleeding if further intervention inappropriate
Dementia

- Inability to dress and/or walk without assistance
- Urinary and faecal incontinence
- No consistent meaningful verbal communication

and at least one of:

- Difficulty swallowing/eating, weight loss (>10% loss over six months)
- Recurrent urinary and/or respiratory infections
- Multiple stage III or IV decubitus ulcers
- Symptoms causing distress

Other situations include:-

- Multiple co-morbidities with no primary diagnosis
- Patient medically unfit for surgery for life-threatening disease
- Failure to respond to Intensive Care and death therefore inevitable
Appendix: Scales and Scores referred to in guidance.

1. WHO Performance Scale
   0: Able to carry out all normal activity without restriction
   1: Restricted in physically strenuous activity, but ambulatory and able to carry out light work
   2: Ambulatory and capable of all self-care, but unable to carry out work; up and about more than 50% of waking hours
   3: Capable only of limited self-care; confined to bed more than 50% of waking hours
   4: Completely disabled; cannot carry out any self-care; totally confined to bed or chair

2. Karnofsky Performance Scale
   100 Normal, no complaints, no evidence of disease
   90 Able to carry on normal activity; minor symptoms of disease
   80 Normal activity with effort; some symptoms of disease
   70 Carers for self; unable to carry on normal activity or active work
   60 Requires occasional assistance but is able to care for needs
   50 Requires considerable assistance and frequent medical care
   40 Disabled: requires special care and assistance
   30 Severely disabled; hospitalization is indicated, death not imminent
   20 Very sick, hospitalization necessary; active treatment necessary
   10 Moribund, fatal processes progressing rapidly

3. The New York Heart Association (NYHA) Functional Classification
   Class I (Mild): No limitation of physical activity. Ordinary physical activity
   Class II (Mild): Slight limitation of physical activity. Comfortable at rest, but ordinary physical activity results in fatigue, palpitation, or dyspnoea
   Class III (Moderate): Marked limitation of physical activity. Comfortable at rest, but less than ordinary activity causes fatigue, palpitation, or dyspnoea
   Class IV (Severe): Unable to carry out any physical activity without discomfort
Symptoms of cardiac insufficiency at rest. If any physical activity is undertaken, discomfort is increased.

References: