Specialist Palliative Care Referral for Patients

This guideline covers referrals for patients with progressive terminal illness, whether due to cancer or other disease.

For many patients in the late stages of their illness, palliative care needs are straightforward and met by the Primary Care and/or Specialist Team. However, if there are complex symptom control or psychosocial issues present or predictable, then advice from or involvement with the Specialist Palliative Care Services should be considered.

Joint working will be important in many cases in order to share specialist knowledge and experience, particularly for non cancer diagnoses.

Specialist Palliative Care Team (SPCT) - available during Office Hours

a) Macmillan Consultant in Palliative Medicine
   Specialist Palliative Care Nurses
   Via **Macmillan Secretary** at:
   - Henbury Building, Macclesfield District General Hospital, Victoria Road, Macclesfield, SK10 3BL
   - Telephone: (01625) 663177
   - Fax: (01625) 661378

a) Macmillan Lung Cancer Nurses
   - Ward 3/4 Corridor, Macclesfield District General Hospital, Victoria Road, Macclesfield, SK10 3BL
   - Telephone: (01625) 661997
   - Fax: (01625) 663240

b) Macmillan Pharmacist
   - Pharmacy Department, Macclesfield District General Hospital, Victoria Road, Macclesfield, SK10 3BL
   - Telephone: (01625) 661183
   - Fax (pharmacy department): (01625) 661065

e) Specialist Palliative Care Physiotherapist
   Specialist Palliative Care Occupational Therapist
   - Dorothy Pearson Unit, East Cheshire Hospice, Millbank Drive, Macclesfield, SK10 3DR
   - Telephone: (01625) 665689
   - Fax (Hospice): (01625) 612611

Note: to contact East Cheshire Hospice
Inpatient Unit, Dorothy Pearson (Day) Unit, Lymphoedema Nurse Specialist
- Address: Millbank Drive, Macclesfield, SK10 3DR.
- Telephone: (01625) 610364
- Referrals to Inpatient Unit or Dorothy Pearson (Day) Unit on Hospice Referral Form to above address – fax if urgent to (01625) 665697
- If further forms needed, please contact Hospice directly

24 hour Advice Line at East Cheshire Hospice: (01625) 666999

Advice or Discussion

This may be, for example, advice on the use of a particular drug or service, or a wider discussion of patients' current and predicted situations, to examine what further treatment or other help may be open to the team caring for them.
By telephone or personal discussion with appropriate member of team. Alternatively, the situation could be discussed with the team at the weekly MDT (currently Wednesday 09:30 to 10:30 in the Cancer Resource Centre – contact the Macmillan Secretary on (66)3177 for details).
Advice out of hours is available to clinical staff by contacting East Cheshire Hospice on (01625)666999 and speaking to the Senior Nurse on duty.

Discussion

This may be by arrangement for face to face discussion with members of the team. This could usefully be done in the MDT meeting.
For tertiary units outside East Cheshire then discussion may take place by telephone.

Joint Working

This requires an initial discussion as above. The teams plan their roles in the patient's care and either assess together or ensure full communication throughout their joint involvement. The patient and carers are made aware of who has responsibility for what aspect of care.

Assessment

This involves a single review of the patient by the appropriate member of the Specialist Palliative Care Team. This may be for advice on a specific aspect of care – e.g. a review of symptom control by the consultant – or to aid discussion about the direction of care. The request for assessment may repeated as and when new situations arise.
By telephone, fax or letter to the palliative care team, or following discussion as above.

Full Involvement of Specialist Palliative Care Team in Care

This is where a member or members of the Specialist Palliative Care Team is asked to take over the full specialist aspect of the patients care, working **alongside** the Primary Care or Hospital Consultant led team. This may be a temporary arrangement or continue for the remainder of the patients' illness.
This would follow discussion of the patient between the specialist and palliative care teams.

Hospice Referral

Following the above, referral for In-patient care or Day Care at the Dorothy Pearson Unit may be advised. The referring Specialist Team will often remain involved, working jointly with the Day Care or Hospice Staff. Updated written guidance on who and how to refer to East Cheshire Hospice will be distributed in January 2008.
Referrals should be made directly to the Hospice on the appropriate referral form (usually East Cheshire Hospice) by the patient's GP in the community or a member of the Consultant medical team if in Hospital.
If the patient is from outside the catchment area of East Cheshire Hospice (Eastern Cheshire – inpatient and day care; High Peak – inpatient) then the Palliative Care Team can advise on who and how to contact if required.

Referral Criteria for the Specialist Palliative Care Team (Hospital and Community)

Palliative care is shared with the Primary Care team and/or Specialist team. Involvement may be for the duration of a particular problem or ongoing until death and bereavement.

General Criteria

All of the below

- Progressive incurable disease *or* the patient has refused treatment if competent to do so
- Prognosis is less than a year (but see additional groups below)
- There are 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 team if competent to choose
- Patient is registered with an Eastern Cheshire practice *or* cared in an East Cheshire Hospital

Additional Groups – may be referred and discussed individually with members of the team as to appropriateness of 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 short prognosis. However, it is recognised that there are "grey areas" and members of the team will be happy to discuss such patients.

Inappropriate referrals include:

- 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 their underlying disease
- Those whose problems are principally psychological and need specialist psychiatric referral, whether or not they have declined such help

However, team members may offer advice on a "one off" basis to the responsible team if there are particular problems and the appropriate specialist team is not available.

The following is intended to provide guidance to patients who may be appropriately referred to the Specialist Palliative Care Team. 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 Team may be appropriate:

General Indicators

At least one of:

- Progressive deterioration in performance scale (e.g. WHO or Karnofsky –appendix 1 and 2)
- Dependence in 3 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 *and*
- Complex symptomatic or psychosocial problems

Cardiac Disease

At least one of

- advanced heart failure (New York Heart Association Grade 3/4 – see appendix 3)
- three 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

- 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*
- 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 > 5seconds above control
- Encephalopathy
- Recurrent variceal bleeding if further intervention inappropriate

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

And at least one of
- Difficulty swallowing/eating; weight loss (>10% loss over 6 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

References:

Suggested Prognostic Indicators of Advanced Disease. Keri Thomas, Jill Main, Amanda Free. From Gold Standards Framework website.
http://www.goldstandardsframework.nhs.uk/content/non_cancer/suggested_prognostic_indicators_of_advanced_disease.pdf (accessed 28/9/6)

End-Stage Disease Indicators. Community Hospices, Maryland.
http://www.communityhospices.org/_assets/TWH_indicator_crds6.pdf#search=%22end-stage%20disease%20indicators%20maryland%22 (accessed 28/9/6)

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 Cares 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 does not cause undue fatigue, palpitation, or dyspnoea (shortness of breath).
- 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.

4: Medical Research Council (MRC) dyspnoea scale

(Bestall, J et al (1999) Thorax; 54:581-586)

- Grade 1 - ' I only get breathless with strenuous exercise'
- Grade 2 - ' I get short of breath when hurrying on the level or up a slight hill'
- Grade 3 - I walk slower then people of the same age on the level because of breathlessness or have to stop for breath when walking at my own pace on the level'
- Grade 4 - ' I stop for breath after walking 100yds or after a few minutes on the level'
- Grade 5 - ' I am too breathless to leave the house'