



East Cheshire Hospice
Making every day count

**REFERRAL GUIDE AND
CRITERIA FOR EAST
CHESHIRE HOSPICE
SERVICES**

Introduction

These guidelines concord with the agreed core referral and discharge criteria for Specialist Palliative Care services within the Greater Manchester and Cheshire Cancer Network. They have been adapted to suit the needs of patients East Cheshire, whilst retaining the core criteria.

Palliative Care is relevant for patients with progressive, life threatening and incurable disease, such as metastatic cancer, organ failure (end stage cardiac, renal, respiratory, liver disease) or neurological disorder. It may be part of the overall approach to care, working alongside other specialist services, or it may be the primary approach to care in the later stages of the disease.

The palliative care needs of many patients can be met by primary care and/or hospital services. Specialist palliative care is appropriate for patients and carers with more complex needs.

Referral to the Specialist Palliative Care service should be with the patient's informed consent if they have the capacity to give or withhold this. If the patient is unable to do so due to lack of capacity, the referral should follow a "best interests" decision (Mental Capacity Act 2005) and be discussed with the patient's legally appointed representative, if appointed, and family/carers.

Service and Population Covered:

East Cheshire Hospice

- Patients registered with GPs in Eastern Cheshire (in patient and day unit)
- Patients registered with GPs in the High Peak area (in patient unit)
- Requests for Patients from out of these areas may be considered on an *individual* basis

Specialist Palliative Care Team

- Community – patients registered with GPs in the Eastern Cheshire sector except Holmes Chapel
- Macclesfield District General Hospital including Psychiatric wards – any in-patient meeting the referral criteria
- Consultant Outpatient Clinic – as above; patients registered with GPs in the Eastern Cheshire sector, including Holmes Chapel Health Centre (if linked with other Eastern Cheshire services) on request

Timing of Referral to Specialist Palliative Care services

A referral may be appropriately made at any point in the patient pathway if the patient has **Specialist Palliative Care** needs.

Key triggers to a referral include:

- The time of diagnosis
- During or on completion of cancer or other disease specific treatments
- Disease progression
- Disease recurrence or relapse
- Recognition of the last 12 months of life
- Recognition of the last days/weeks of life

Referral Criteria and Guide

Introduction

East Cheshire Hospice provides Specialist Palliative care for people with progressive life limiting illness and support for their families and carers, given by a multi-professional team.

Referrals should be based on the individual's needs rather than diagnosis – the

Hospice provides care for patients with malignant and non-malignant disease.

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Criteria for referral to Specialist Palliative Care Services

Core criteria for all SPC services.

The patient has advanced progressive life-limiting illness and at least one of the following:

- Difficult pain or other symptom control
- Complex psychosocial problems (patient/carer)
- Need for specialist end of life care and support, which may include bereavement care
- Need for specialist help with rehabilitation or adjustment to deteriorating function
- Generic (generalist) services are unable to meet the patient/carer needs
- The problems identified are best dealt with by the Hospice In- patient or Day Hospice Service
- The patient agrees to referral to the Hospice if competent to choose
- The patient is registered with a family practice within Eastern Cheshire CCG or North Derbyshire CCG
- Aged 18 years or over.

East Cheshire Hospice Inpatient Care

Where specialist multidisciplinary palliative inpatient care is required because management is proving difficult in other settings, and the patient does **not** require acute hospital care, and:

- The patient requires specialist medical or nursing assessment
- Planned care for those with complex medical and nursing needs, including poor symptom control
- Need for specialist rehabilitation,
- Complex needs in the last days of life

However, it is recognised that there are “grey areas” where individuals have needs but do not fit all the criteria above.

Such patients may be referred and discussed individually with the team as to appropriateness of referral.

For example:

- A patient with progressive disease with a longer prognosis than one year but who has complex needs
- Someone needing extra support around the time of diagnosis of incurable but treatable disease.

Note: that referral to the Hospice service does not preclude involvement of Specialist Teams – continued participation and collaborative care is welcomed, particularly in complex conditions. It is recognised that certain interventional treatments cannot be given on site, and transfer to the hospital may be necessary if such treatments are needed.

See appendix 1 for suggested referral criteria for particular types of illness

Note: the Hospice does not provide long term care. Please make sure that during the referral process the patient is made aware of this prior to admission.

Referrals are accepted for:

- Symptom control
- Complex needs
- Optimization following palliative interventions or acute episode due to disease progression
- End of life care

Criteria for Admission to services

- The patient has complex needs as outlined in the criteria for Specialist Palliative Care services
- The patient has been provided with information about the service and has consented to the admission
- The patient's needs are best met by specialist palliative care, and acute hospital care is not required and/or not wanted by the patient.

Referral Procedure

Planned admissions normally occur daily, Monday to Friday. **Out of Hours Admissions** may be requested for emergencies. The referring team must contact the senior nurse on duty by telephone. The decision as to whether to admit or not is made by agreement between the Senior Nurse and Doctor on call. Up to date written information must accompany the patient and a completed referral form should be faxed to the hospice at the time referral is accepted. The patient's current medication should be brought in.

Referrals are accepted from team members/nurses, specialists and self-referrals with the consent of the GP or Consultant.

The East Cheshire Hospice Referral Form should be completed and posted or faxed.

Admissions are prioritised according to need. Further information may be required to help this, depending on what information has been supplied on the referral form. Deferred referrals/On Hold may be made for patients who are likely to need admission in the future. If admission is requested at a later date, a written update should be sent to the hospice.

Details of patients on the deferred waiting list will be reviewed at intervals, and updated information may be requested. If no admission is requested within 6 months of the referral, the details will be removed from the list.

Transfer of Patients to the Hospice

1. The referring health care team is responsible for ensuring that the patient is fit for transfer to the Hospice
2. The referring team must arrange suitable transport
3. The team must also inform the patient and carers of the admission arrangements
4. If a decision that resuscitation should not be attempted in the case of cardio-respiratory arrest (“DNAR”), the ambulance team must be informed and the DNAR document sent with the patient
5. Patients transferred from Macclesfield District General Hospital should be accompanied by the hospital case notes including the current medication chart; or from other units, by legible photocopied notes and transfer documentation.
6. Patients admitted from the community should be accompanied by relevant copies of community, medical and/or nursing documentation
7. All current medication must be brought in with the patient

Discharge will be arranged when:

- The specialist palliative care needs of the patient have been met
- The patient’s needs can be met by their primary or social care professionals, or both, or care home staff if living or moving there.
- It is requested by the patient. Every effort will be made to facilitate a supported and timely discharge in accordance with the patient’s wishes
- Discharge planning is conducted in collaboration with relevant professionals, the patient and carers.

Note - Should the patient no longer need Specialist Palliative Care they may be discharged, to the ongoing care of community or hospital services, regardless of the stage of the disease.

Sunflower Centre

Referral Criteria

- Diagnosis of progressive life-limiting illness
- Complex palliative care needs that cannot be met by current health/ social care professionals
- Well enough to attend the Sunflower Centre
- Can be transported to the Day Hospice safely via family & friends, specialist taxi/ well enough to get into a car unaided when supported by volunteer drivers / ambulance transport if accepted by ambulance service
- The patient wishes to attend

Referrals are accepted for:

- Symptom control
- Complex psychological and/or social needs
- Optimization following palliative interventions or acute episode following disease progression
- Difficulty coping with a potentially life limiting illness

Referrals may also be made for outpatient appointments for the following:

- Physiotherapy
- Occupational therapy
- Art Therapy – Psychotherapeutic
- Complementary Therapies
- Breathlessness Clinics
- Fatigue Management
- Living Well

Day Services

- The patient and their carer will be invited to attend for an initial assessment, at the Sunflower Centre, whereby they will have the opportunity to discuss their concerns and have their needs identified.
- Following on from this assessment we will work with the patient to develop a personal care plan, referring on to appropriate services within the hospice. This will be subject to ongoing review by appropriate members of the team.
- Placements are offered for up to 12 weeks at a time and each person is reviewed after this period. If the person's condition is stable we will then plan for discharge.
- There are a wide range of services available within the Sunflower Centre. People may attend for the full day or for part of the day, dependent upon their individual needs.
- The team will liaise with other health and social care professionals as appropriate in the hospice, community or hospital.

Referral Procedure

- Referrals may be made by General Practitioners or Specialist Nurses. They may also be initiated by the patient, family members or other professionals, (e.g. District Nurses, Hospital Medical teams, Social Care teams). However, the General Practitioner will always be informed that the patient has been referred and is accessing our day hospice services.
- Referral is by completion of an East Cheshire Hospice referral form

Discharge will be arranged when

- The specialist palliative care needs of the patient have been met
- The patient's needs may be met by their primary or social care professionals, or both

- Outstanding needs do not fall within the Day Hospice criteria
- The patient is not well enough to attend
- The patient no longer wishes to attend

Lymphoedema Clinic

Aim of treatment

- To reduce and/or manage the patient's lymphoedema by providing high quality clinical care, following national guidelines
- To educate and support patients and/or carers to enable them to manage the condition themselves
- To manage associated symptoms of lymphoedema, such as discomfort, cellulitis, or reduced limb function
- To liaise with appropriate health care professionals and other agencies to facilitate on-going support for patients

Referral Criteria

- Lymphoedema secondary to cancer or its treatment
- Lymphoedema secondary to other progressive life limiting illness that fulfils criteria for referral to the Sunflower Centre or In-patient Unit

Referral Procedure

- Referrals may be made by health care professionals involved with the patient's care, with the agreement of the patient and General Practitioner or Hospital Consultant
- Referral is by completion of a Hospice referral form, which should be signed by a doctor

Note: if the patient has active disease, we may require further information from the patient's doctors, to eliminate contra-indications to treatment

Discharge will be arranged

- If there is no possibility of making an impact on the patient's needs
- If the patient declines further treatment or repeatedly misses appointments
- If the lymphoedema resolves spontaneously (rare)

Physiotherapy and Occupational Therapy Team

Referral Criteria

Diagnosis of progressive life-limiting disease requiring assessment and/or treatment by a specialist physiotherapist or occupational therapist. For example:

- Weakness, fatigue
- Neurological deficit
- Difficulty with the activities of general living, mobility, moving and handling issues.
- Access issues at home
- Breathlessness management
- Pain
- Restrictive scar tissue following surgery
- Symptoms that may be treated by acupuncture, such as pain, hot flushes

Access

- The service offers domiciliary as well as hospice based therapy Occupational Therapy
- Domiciliary Palliative Physiotherapy is accessed via the East Cheshire Macmillan Team

Referral procedure

- Referrals may be made by Health Care Professional involved with the patient's care, with the consent of the patient and the General Practitioner or Hospital Consultant
- Referral is by completion of an East Cheshire Hospice referral form

Discharge

- When no further intervention is required the patient will be discharged into the care of community services regardless of the stage of disease.
- Patients may be re-referred following discharge should the service be required
- If the patient declines further treatment

Appendix 1

Indicators that referral to the Hospice may be appropriate:

General

At least one of:

- Progressive deterioration in physical ability
- Dependence in 3 or more activities of daily living
- Multiple co-morbidities
- Symptoms 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

- Cancer

Incurable metastatic disease or inoperable disease and
Complex symptomatic, psychological and/or social problems

- Cardiac Disease:

At least one of

- Advanced heart failure (New York Heart Association Grade 3/4 see below)
- Three or more hospital admissions in last 12 months with symptoms of heart failure
- Physical or psychological symptoms despite optimal tolerated therapy
- Symptomatic arrhythmias resistant to treatment the patient does not want cardiopulmonary resuscitation in the event of an arrest

- Pulmonary Disease

At least one of

- Shortness of breath at rest or minimal exertion (MRC grade 4 or 5 – see below)
- Documented progressive disease
- Symptomatic right heart failure

- Renal Disease:

Unable/ unwilling to undergo dialysis or transplant & at least one of: •Patient wishes to stop dialysis

- Signs of renal failure (nausea, pruritus, restlessness, altered consciousness)
- Intractable fluid overload
- Rapid deterioration anticipated by renal team

- Neurological Disease

Significant progressive decline in function

- Unable to walk
- Dependent 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

- Liver Disease

- Ascites despite maximum diuretics; spontaneous peritonitis
- Jaundice
- Hepatorenal syndrome; PTT > 5seconds above control
- Encephalopathy
- Recurrent variceal bleeding

- 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, death therefore inevitable

Scales and Scores Referred to in Guidance

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.

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

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.

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 than 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'

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 2 - Contact Details

East Cheshire Hospice

- Millbank Drive, Macclesfield, SK10 3DR
- Telephone: (01625) 610364
- Fax: (01625) 665697
- Referrals to: Inpatient Unit, Sunflower Centre on Hospice Referral Form to above address – fax if urgent and confirm receipt by telephone
- If further forms needed, please contact Hospice directly and a form may be faxed

24 hour Advice Line at East Cheshire Hospice:

- (01625) 666999

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

Macmillan Specialist Palliative Consultant and Nursing Team at

- Macclesfield District General Hospital, Victoria Road, Macclesfield, SK10 3BL
- Telephone: (01625) 663177
- Fax: (01625) 661378

Macmillan Lung Cancer Nurses

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

Macmillan Pharmacist

- Pharmacy Department, Macclesfield District General Hospital
- Telephone: (01625) 661183
- Fax (pharmacy department): (01625) 661065

East Cheshire Crossroads Macmillan Palliative Care Service

Offers practical support for carers where and when needed, usually in the home

Contact: Anthea Frank, East Cheshire Crossroads (9-5 Mon-Thu; 9-4:30 Fri)

- Sunderland House, Sunderland Street, Macclesfield SK11 6JF

- Tel: 01625 511044
- Fax: 01625 511099
- Email: afrank@eastcheshirecrossroads.org.uk
- help@eastcheshirecrossroads.org.uk

East Cheshire Hospice thanks St Ann's Hospice (Heald Green and Little Hulton) for permission to use their Referral Criteria document as a template for our own.