



**East Cheshire
Hospice**

East Cheshire Hospice at Home Service Specification

PURPOSE

Aims

The aim of the collaborative service is:

- To provide practical care and emotional support in the last 6-8 weeks of life, with the priority given to those in the terminal stage (the last days of life), to the general practice registered population of East Cheshire.
- The service providers will work in collaboration with each other as well as existing NHS service (District Nurses, Intermediate Care, Marie Curie, Macmillan, and Continuing Health Care).
- The service will support the delivery of the Care Plan for End of life, with the overall aim being to enable patients at end of life to achieve their preferred place of care and death in the context of dignity and comfort.
- The service will provide an equitable service to all patients with need, including hands on practical and social support, rapid and planned response with specialist assessment during the out of hours period.
- The service will be complementary to the district nursing service and will work in partnership to provide seamless care.
- To increase the number of patients who die at home
- The service will be available to all on the basis of need not diagnosis.

Evidence Base

- NICE Guidance (2004) improving Supportive and Palliative Care for Adults with Cancer.
- Department of Health; Our NHS Our Future
- Department of Health; National End of Life Care Strategy
- White Paper; Our Health, Our Care, Our Say, focusing on the development pathways in the community
- Building on the Best' document recognising the importance of choices at the end of life, Dec 2004
- National Audit Office; Report on End of Life Care 2008
- NHS England; Actions for End of Life 2014-16
- National Forum for Hospice at Home 2007

General Overview

The service will be provided by working in partnership with already established services to support patients and enable them to die in their preferred place of care acknowledging the need to identify patient choice.

NHS England; Actions for End of Life 2014-16 document states approximately ½ million people die each year, with three quarters of deaths expected. High quality end of life care is required and can be facilitated by health care professionals providing they have time, education, training and support. Around half a million carers provide care to people at end of life with a proportion of these people having complex needs that require access to support and advice from healthcare professionals trained in specialist palliative care.

In 2012 a British Social Attitudes survey highlighted that 60% of people who stated that they would wish to die at home would actually change their minds if there was insufficient support from family, friends and health care professionals. 28% wished to be in the presence of family and friends and 24% stated they wished to be pain free.

All Patients at the end of life should have an individual needs assessment, care plan and provided, enabling them to die supported in their chosen place of care (Palliative and Supported Care Strategy for NHS Birmingham East and North, 2007).

Objectives

The main objective is to facilitate a dignified and comfortable end of life if the patient's preferred place of death is their home. Carers need to be included in negotiations as support for them is often necessary to fulfil the patient's preference for care.

East Cheshire Hospice @Home (H @H) is a collaborative service and will assist in providing emotional and practical nursing support in the last days of life, as a priority, and where prognosis is anticipated to be a few weeks. A high level of communication is required between all health care professionals involved in the patient's care, and they will aim to facilitate the following:

- To increase the number of patients that wish to be looked after in their preferred place of care.
- To reduce inappropriate admissions and enable patients to be discharged from hospital or hospice where appropriate particularly in the last few weeks of life.
- To facilitate and increase the number of patients that die at home if that is their choice.
- To provide an equitable service to all who require it across East Cheshire.
- To act as a source of specialist advice and support to generalist staff.

Expected Outcomes

- Increase the number of deaths at home or the patients preferred place of care
- Reduction of inappropriate admissions
- Increased numbers of patients with a palliative diagnosis other than cancer being cared for at home, eg. Heart Failure, respiratory failure, neurological disorders, dementia, frailty and elderly
- To decrease the number of patients that die in hospital
- Meeting the standards for End of Life Care

As a new service, East Cheshire Hospice @Home service will be required to demonstrate that it meets the needs of the patients and their families and that it is done in an effective and efficient way.

Using the Outcome Assessment and Complexity Collaborative suite of measurement tools (OACC) recommended by Hospice UK and the Cicely Saunders Institute, East Cheshire H @H Service aims to capture and demonstrate the impact of palliative care in a validated way.

Additionally, East Cheshire Hospice will be commissioning an external body to undertake longitudinal review through a service mapping approach.

SCOPE

Service Description

- The team will offer specialist skills of hospice staff in a person's home, providing support at night and during the weekend hours.
- The team will consist of trained nurses and health care assistants.
- Hospice @Home works collaboratively with other health and social care providers aiming to work in conjunction with, and in addition to such services, utilising open and free communication between organisations.
- The integrated service will provide End of Life care incorporating the NICE guidance and using the End of Life tools. The service will be integral to the existing tools such as the Care Plan for End of Life, the Gold Standard Framework and the Preferred Priorities of Care.
- Where involved, the community key worker eg. District Nurse, Community Matron etc. will retain autonomous responsibility for co-ordinating care requirements. Other key professionals may be Continuing Health Care Co-ordinator, Social Worker or Macmillan nurse.
- Referrals will be accepted either by the H @H co-ordinator, or can be made directly to the H @H team by any health care professional working within East Cheshire, the referral can be faxed directly, emailed or taken over the telephone.
- The referral information needed contributes to a key aspect of co-ordinating care services and enables the registered nurse to review and assess the current care provision which will enable appropriate prioritisation and allocation of resources.
- Once a referral is received and accepted, arrangements will be made for a trained nurse to visit and carry out a first assessment, ideally, prior to care commencing. If a patient has not had a first assessment carried out and is in crisis, staff will still be able to attend and conduct the first assessment during the emergency visit.
- Referrals will always be followed up with a phone call to the referrer to facilitate a timely response and gain more information verbally over the phone if required.
- Where relevant, patients who are waiting to be admitted to the hospice/hospital or wish for rapid discharge home and are awaiting care packages, can be supported by the H@H team until the care provision is available.
- Practical nursing care and emotional support will be provided between the hours of 6.30pm – 8am Monday – Friday and over the 24-hour period at weekends. Bank Holidays will be reviewed, and a service provided dependant on patient need.
- H@H will provide rapid and planned response to patient need regardless of diagnosis at end of life.
- Hospice @Home will provide Rapid Response when required to prevent inappropriate admissions to hospital at end of life.
- H@H will provide access to specialist palliative advice
- A patient information pack will be provided and given to the patient and their family at the commencement of the service.
- H@H will provide pre-bereavement support and bereavement follow-up can be arranged with other key healthcare professionals as appropriate. Carers and relatives will be supported and invited to attend the remembrance and light up a life services.
- Ongoing audit and governance to be in place across the organisation to establish ongoing standards of practice.

Referrals may be declined if it is deemed that the needs of the patient **do not** fit the criteria. In these instances, the referrer and main keyworkers will be contacted.

Accessibility/Acceptability

East Cheshire H@H will ensure a seamless approach to the delivery of care via agreed communication systems upon receipt of referral. At all times, H@H will ensure that the District Nurse will retain responsibility for the care of the patient and that Marie Curie continues to be first point of contact when organising night sits.

Palliative and End of Life patients will be assessed and identified by their General Practitioner/District Nurse (GP/DN), Specialist Nurse, Hospital Consultant or other Health Care Professional (HCP).

Patients will access the service through:

- Referral from HCP/GP
- Specialist Nurse
- Referral from Hospital
- Referral from DN service
- Self-referral supported by GP
- Care Homes and Nursing Homes

East Cheshire H@H Service will be required to demonstrate compliance and monitoring of:

- Equity of access to service for all vulnerable groups within East Cheshire.
- Reflect a duty to promote racial equality both in service delivery and workforce policies.

Whole System Relationships

East Cheshire H@H Service will work in partnership with GP's, DN's, the Acute Trust and Out of Hours services across East Cheshire, Marie Curie and other Health Care providers within the system, to ensure seamless patient care.

Interdependencies

- General Practice
- Community Nursing Team
- Hospice Services
- Community Pharmacies
- Out of Hours Urgent Care Services
- Hospital Services
- Therapy services
- Bereavement Services
- North West Ambulance Service
- Chaplaincy Services
- Marie Curie
- Commissioners

Relevant Networks and Screening Programmes

Sub-Contractors

The service does not currently use sub-contractors in the delivery of any aspect of service delivery.

SERVICE DELIVERY

Service Model

This Model will include Registered Nurses and Health Care Assistants to provide a mix of specialist assessment, hands on care, and ongoing skilled care. This will be linked with the multidisciplinary team and Hospice services.

REFERRAL, ACCESS AND ACCEPTANCE CRITERIA

Geographic Boundaries

This service is operational across East Cheshire.

Location of Service

The service is available to patients in their own home wherever it is deemed to be.

Days and Hours of Operation – To cover 5 nights per week in conjunction with Marie Curie

MON	TUE	WED	THUR	FRI	SAT	SUN
Co-ordinator 9.30-5.30pm Night shift Rapid Response 6.30pm- 8.00am	Rapid response 24 hours	Rapid response 24 hours				

Night sits will be between 10.30pm and 7.30am dependant on need and availability of staff.

Referral Criteria and Sources

- East Cheshire H@H service will enable all adults (18 years and upwards) who have a life limiting illness to be cared for at home and to die at home if that is their choice.
- Patients will have a preferred place of care as home, have family and carers in support of this and where possible advanced care plans in place.
- DNACPR should be actively explored for patients who are referred to the hospice at home service, particularly those referred for symptom control at EOL and whose PPD is home.
- Patients should be estimated to be in the last 6-8 weeks of life.
- It is preferable that patients have the appropriate paperwork in place to support the administration of end of life medications and to authorise nurse verification of death.

The care provided will cover 5 key areas:

1. Symptom management/support
2. Complex social support
3. Psychological and or spiritual support
4. Care and support for families and friends
5. Rapid intervention to support them to remain at home or to return home

Referral Route

Referrals will be made via email fax/telephone within the service provider and will be monitored accurately with the record of the following made as a minimum:

- Source of referral
- Primary Diagnosis
- Reason for Referral
- Urgency of response

Referrals will be received from any Health Care Professionals within East Cheshire, predominantly District and Macmillan Nurses. Patients and Carers may also self-refer if the GP is aware.

When a referral is received the referrer will be notified. Contact with the key worker will be made before any service is provided to ensure sharing of information and partnership working.

Exclusion criteria

- All patients under the age of 18
- Patients who do not meet the criteria for inclusion on the gold standards register
- Patients' who are not registered with a GP within East Cheshire
- Patient's with no life limiting illness except the frail/elderly at End of Life
- Patients who have had chemotherapy and or radiotherapy in the last 14 days (oncology advice should be sought first)
- Patients who have been assessed as a risk to staff (each situation will be assessed on an individual basis).

Patients who are not thought to be in the last 6-8 weeks of life do not fit the criteria for Hospice @Home, although an on-hold referral can be sent so the patient information is available in case of rapid decline and crisis intervention is needed.

Response Time and Prioritisation

There will be a same day response for urgent patient need and a RAG tool will be used to assess and respond to other patient need.

- **RED – high/urgent needs – rapid change in condition, complex symptoms in the last hours or days of life, rapid discharge, carer crisis, pre-admission – rapid response to need within 30 minutes -1hour**
- **AMBER – deterioration in the last days or weeks of life, awaiting care package, potential breakdown foreseen, respite for carers – discussion with referrer and planed call to patient/family within 2 hours of receipt of referral.**
- **GREEN – may not be appropriate for Hospice @Home at this stage, or the team can make contact and hold on file**

Assessment of urgency will be carried out and agreed between the service assessor and the referrer.

Priority will be given to patients fulfilling the criteria for the end of life care pathway, usually in the last few days to 2 weeks of life. A framework for prioritisation is used as a guide to support clinical decision making.

If the patient requires further ongoing personal care then a referral will be made to an appropriate care provider.

DISCHARGE CRITERIA AND PLANNING

Discharge Criteria

The service decides that a patient is ready for discharge if the patient is stable, able to self-care or the prognosis improves.

Patients may be discharged from the service when:

- the patient's condition no longer meets the service criteria, however if any patient should require the service in the future a re-referral can be made.
 - the family express no input is required
 - the patient is admitted to another inpatient setting or their care can be met by another community care provider
 - the hospice multi-professional team, in conjunction with the patient and their family, agree the service input is no longer beneficial
 - the patient dies
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- Assessment and planning is undertaken
 - Referral to other agencies if needed
 - Contact with GP/Key worker
 - Ensuring that the patient / carer knows who to contact if their needs change and they have concerns

SELF-CARE AND PATIENT CARER INFORMATION

The service will develop and make clear and up-to date information, which is accessible and appropriate for all members of the population.

The service will support patients and their carer to assist in their self-management by signposting to all professional and voluntary sector organisations for support and advice as necessary.

QUALITY AND PERFORMANCE STANDARDS

Expected Outcomes

The OACC suite of outcomes can be divided into six measurement tools.

1. **IPOS** - Integrated Palliative Care Outcome Scale is a measure of physical, psychosocial, social and spiritual wellness in line with a full holistic assessment. IPOS allows patients to list their main concerns, to add any other symptoms they may be experiencing and to state whether they or their family have unmet information or practical needs. IPOS is coded within EMIS & ECH templates have been built. The IPOS has been shown to be valid and reliable as a clinical tool, and is used to measure the global symptom burden that patients encounter when entering the end stage of their lives. IPOS can be completed by the patient or staff, and when completed the severity of the problems can be assessed through discussion with the patient or their family. The information collated will be used to monitor the effectiveness of service interventions and improve patient's quality of care.
2. **Phase of Illness** – Describes the patients distinct stage in illness (see table below). It is recommended that the phase of illness is recorded at first assessment / on admission, at subsequent assessments during spell of care (every 3 days) and at discharge from service. Phases are classified according to the care needs of the patient and their family, and give an indication of the suitability of the current care plan. At East Cheshire Hospice [ECH] we also record phase of illness at the weekly Multi-Disciplinary Team meeting. Phase of illness is coded within EMIS & ECH templates have been built.

	This is the current phase if...	This phase ends when...
Stable	Patient's problems & symptoms are adequately controlled by established plan of care & further interventions to maintain symptom control & quality of life have been planned & family / carer situation is relatively stable & no new issues are apparent.	The needs of the patient & / or family / carer increase, requiring changes to the existing plan of care.
Unstable	An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care & / or rapid increase in the severity of a current problem & / or family / carer circumstances change suddenly impacting on patient care.	The new plan of care is in place, it has been reviewed & no further changes to the care plan are required. This does not necessarily mean that the symptom / crisis has fully resolved but there is a clear diagnosis & plan of care (i.e. patient is stable or deteriorating) & / or death is likely within days (i.e. patient is now dying).
Deteriorating	The care plan is addressing anticipated needs, but requires periodic review, because the patient's overall functional status is declining & the patient experiences a gradual worsening of existing problem(s) & / or the patient experiences a new, but anticipated, problem & / or the family / carer experience gradual worsening distress that impacts on the patient care.	Patient condition plateaus (i.e. patient is now stable) & / or urgent change in the care plan or emergency treatment & / or family / carers experience a sudden change in their situation that impacts on patient care, & urgent intervention is required (i.e. patient is now unstable) or death is likely within days (i.e. patient is now dying).
Dying	Dying: death is likely within days.	Patient dies or patient condition changes & death is no longer likely within days (i.e. patient is now stable & / or deteriorating).
Deceased	The patient has died; bereavement support provided to family / carers is documented in the deceased patients clinical record.	Case is closed.

The phase of illness provides a clinical indication of the level of care required dependant on the stage of illness the patient is currently at. The information obtained from the measure helps ensure the care plan is modified to incorporate the needs of the family and the patient. During the triage process the phase of illness can help with prioritising the allocation of resources.

3. Australia-modified Karnofsky Performance Status [AKPS] – This is currently coded and used as part of the admission procedure to ECH to determine performance status of patient. AKPS is coded within EMIS & templates have been built. The overall performance status is assessed in three dimensions: activity, work and self-care and provides basic information on overall functional status thus giving an indication of the resources required to care for the patient. The AKPS will be used as an aid for prognostication and discharge planning if required.

4. **Views on Care** – derived from St Christopher's Index of Patient priorities (SKIPP), used to assess the patient's own views on care and quality of life. Views on Care is coded within EMIS and built into ECH templates. The questions assess the patient's own rating of their quality of life and their view of the impact of the service on their main problems. This tool is designed to be used alongside the patient version of the IPOS. The measure will provide staff with an indication of whether or not they are having a positive impact on the patients' lives and is indicative of how the service is affecting this important outcome.
5. **Carers Measures** – Measures the main care giver (unpaid) strain. Each question asks the caregiver to scale how they have been affected by the role of 'Caregiver'. This measure will allow the service to capture the extent of the burden on care givers and if appropriate prompt action to support them in their role. (This is not yet coded on EMIS).
6. **Barthel Index** – (recommended for inpatients) measures the patient's ability to perform 10 common Activities of Daily Living. The Barthel Index is coded on EMIS but no templates have been developed at ECH. **This measure will not be utilised as part of the H@H outcome assessments.**

As established services, the Inpatient Unit and Sunflower Centre at East Cheshire Hospice have already adopted the use of Phase of illness, and are currently in the process of moving towards the utilisation of the Australia-modified Karnofsky Performance Status [AKPS] and IPOS.

East Cheshire H@H will aim to utilise 1-5 tools listed in the above outcomes and will capture the phase of illness, AKPS, IPOS and Carer measure as part of the initial first contact assessment. During each contact, the phase of illness will be reviewed and updated. If the phase of illness changes or the patient is discharged from the service, AKPS, IPOS and Carer measure will need a review and update also.

The Views on Care Measure is to assess the impact of care retrospectively therefore this will not be used during admission process but may be used if there is a change captured in the phase of illness or the end of the spell of care e.g. discharge or death.

The outcome measures will be used to drive quality improvement, deliver evidence on the impact of the service, improve team working, inform commissioners and achieve better results for the patients and their families.

ACTIVITY

Activity will be reviewed on a quarterly basis once data collection systems are agreed and collaboratively implemented.

Activity and Data collection is a priority and fundamental data requirements will be established.

CONTINUAL SERVICE IMPROVEMENT

As part of the monitoring and evaluation procedures, the service will identify a method of measuring to continuously improve the service being offered, and work to ensure unmet need is both identified and brought to the attention of the service lead.

Key Performance Indicators will be set to indicate areas for required development.