

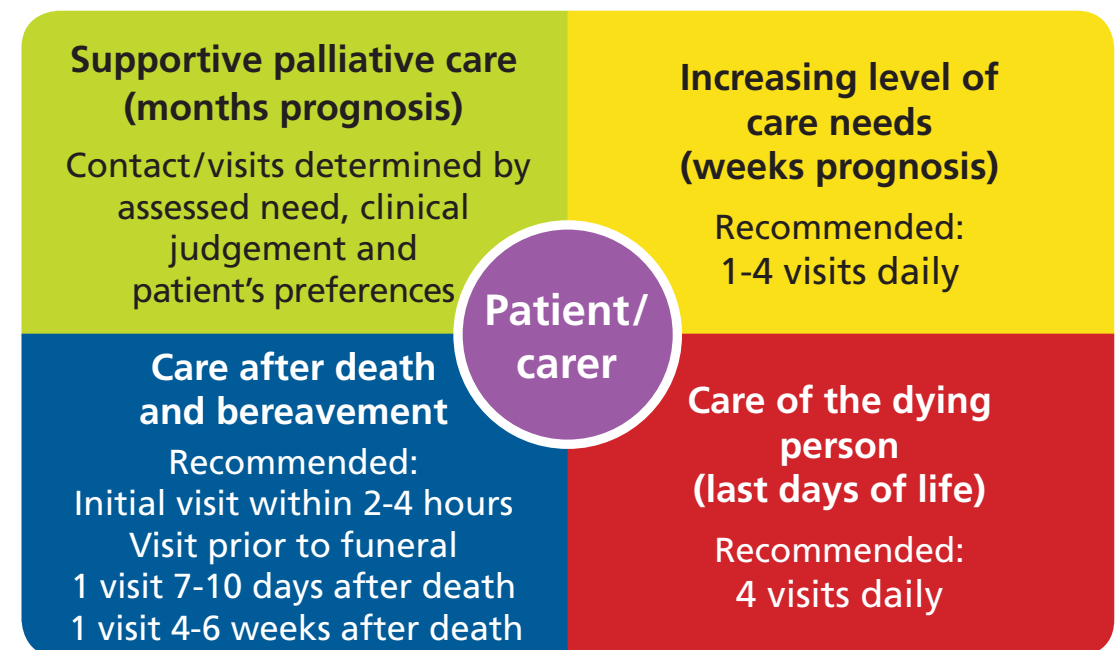
# Service Delivery Framework (SDF) for Integrated Palliative and End of Life Care

The purpose of this framework is to provide a model for meeting the palliative and end of life care needs of patients known to LCH's neighbourhood teams (NTs). The SDF sets out best practice for delivery of this care, however this may vary depending on individual need and preferences.

## The aims of care are to ensure:

- Timely recognition of patients palliative and end of life care needs
- Patients and their families / carers are sensitively communicated with, involved in their care and able to make informed choices
- Patients are offered:
  - the opportunity to discuss their future care and wishes
  - a personalised care plan
  - continuous assessment in response to their changing needs and wishes
- Care is well coordinated 24/7 and delivered by appropriately skilled and experienced staff
- The needs of families / carers are actively explored, respected and met, wherever possible

Service Delivery Framework Model below indicates the recommended frequency of face-to-face visits.



## Key principles

**The following principles underpin delivery of the care outlined throughout this framework:**

- Frequency of contact must be based on assessed need, clinical judgement and patients' preferences
- Repeated telephone contact for patients with palliative and end of life care needs is not acceptable
- Assessment and meeting the needs of a dying patient is not dependent on their Fast Track funding status
- Non-adherence to the framework must be agreed with the Case Manager or deputising senior clinician rationale documented
- Carers should be registered in their own right if needing an assessment of their needs
- The case manager has responsibility for:
  - ensuring appropriate delegation to staff with the right skills and knowledge; this includes NCAs being actively involved in care delivery before consideration is given to requesting agency support
  - promoting continuity of care from the case manager and cluster caseload team
  - ensuring Fast Track funding is reviewed if the patient's condition changes and they are no longer thought to be rapidly deteriorating
  - reflecting and reviewing patient's care after death with the MDT to identify good practice / areas of concern and share learning at cluster meetings, MDT meetings or the LCH Mortality Governance Forum

**Supportive palliative care (advancing disease): Green - months prognosis**

| Care outcome   | Case Manager's Responsibilities<br>(Registered Clinician) or delegated deputy   | Frequency of contact / face-to-face visits   | Night Care  | Medical Social Worker / Joint Care Manager (JCM) Continuing Health Care (CHC)                                   |
|--|---|--|---|---|
| The patient's palliative and end of life care needs are recognised | <ul style="list-style-type: none"> <li>• Sensitive discussion with patient about palliative care approach</li> <li>• Multidisciplinary discussion / agreement</li> <li>• Offer appropriate information e.g. <i>Palliative care: information for patients and carers leaflet</i></li> <li>• Assessment of care needs and personal care plan agreed</li> <li>• Referral / signpost to relevant services e.g. within NT, specialist palliative care / other agencies</li> </ul>  | Contact / visits to be determined by assessed need, clinical judgement and patient's preferences (this must not be repeated telephone contact) | Not usually applicable unless CHC funding in place; discuss with the night service if patient requires support. | Not usually applicable unless care package or CHC funding in place<br>NT to refer if CHC assessment appropriate |
| Care is well coordinated   | <ul style="list-style-type: none"> <li>• Case manager / named nurse identified</li> <li>• Liaison with key staff involved, including care agency and residential care home where relevant</li> <li>• Patient informed about how their information is shared</li> <li>• Patient identified on EPaCCS / GP palliative care register</li> <li>• Discussion at GSF / Palliative Care multidisciplinary and cluster meetings</li> <li>• Review need for Out of Hours (OOH) Handover Form</li> <li>• Provide neighbourhood team (NT) service contact details including OOHs and Palliative Care Line number – pink sticker</li> </ul> |  |   |   |

| Care outcome   | Case Manager's Responsibilities<br>(Registered Clinician) or delegated deputy   | Frequency of contact / face-to-face visits | Night Care | Medical Social Worker / Joint Care Manager (JCM) Continuing Health Care (CHC) |
|--|---|--|------------|---|
| Psychological, spiritual and cultural care needs are met                         | <ul style="list-style-type: none"> <li>• Relationship building with patient and their carer / family</li> <li>• Sensitive exploration of personal beliefs and wishes, including cultural or religious</li> <li>• Identification of any barriers to communication</li> <li>• Recognition of complex needs and referral / liaison with specialist palliative care</li> </ul>  |  |            |   |
| Patient has the opportunity to discuss their future care / advance care planning | <ul style="list-style-type: none"> <li>• Offer advance care planning discussions to explore future care wishes e.g. <ul style="list-style-type: none"> <li>- Any personal wishes or preferences</li> <li>- Who is important to the patient and the extent they wish them to be involved in care discussions / decisions</li> <li>- Cardiopulmonary resuscitation decisions</li> <li>- Preferred place of care / death</li> <li>- Treatment escalation plans</li> </ul> </li> <li>• Offer patient information such as: <ul style="list-style-type: none"> <li>- <i>Planning for your future care</i></li> <li>- <i>Palliative Care: information for patients and carers</i></li> <li>- <i>What to do when my heart stops</i></li> <li>- <i>Preferred Priorities for Care</i></li> <li>- <i>Leeds palliative care website</i></li> </ul> </li> <li>• Record patient's wishes and preferences about their future care on EPaCCS</li> <li>• Involve carers / family to extent the patient's wishes</li> <li>• Consider best interest decision making if lacks capacity</li> </ul> |  |            |   |

| Care outcome   | Case Manager's Responsibilities<br>(Registered Clinician) or delegated deputy  | Frequency of contact / face-to-face visits | Night Care | Medical Social Worker / Joint Care Manager (JCM) Continuing Health Care (CHC) |
|--|--|--|------------|---|
| Comfort and wellbeing needs are met                    | <p>Assessment of needs to include:</p> <ul style="list-style-type: none"> <li>• Social care needs</li> <li>• Symptom management</li> <li>• Nutrition and hydration</li> <li>• Personal care needs</li> <li>• Pressure area care</li> <li>• Mobility, independence and personal goals</li> <li>• Moving and handling</li> <li>• Equipment</li> <li>• Continence</li> </ul> <p>Consider:</p> <ul style="list-style-type: none"> <li>• CHC eligibility and assessment</li> <li>• Referral to specialist palliative care for complex symptom management support</li> <li>• Referral to hospice or integrated NT therapy services to maximise independence</li> </ul> |  |            |   |
| Carers' needs are recognised and met wherever possible | <ul style="list-style-type: none"> <li>• Identification of people important to the patient</li> <li>• Explore concerns and queries</li> <li>• Consider pre-bereavement support</li> <li>• Consider need for carer's own assessment</li> <li>• Sign post and provide information</li> </ul>   |  |            |   |

**Increasing level of care need (deteriorating condition): Amber – weeks prognosis**

| Care outcome                    | Case Manager’s Responsibilities<br>(Registered Clinician) or delegated deputy   | Frequency of contact / face-to-face visits  | Night Care   | Medical Social Worker / Joint Care Manager (JCM) Continuing Health Care (CHC)   |
|---------------------------------|---|---|--|---|
| Increasing level of need is met | <p><b>Sensitive communication</b> with patient and carer / family re deteriorating condition, support available, future care wishes and what to expect:</p> <ul style="list-style-type: none"> <li>• Consider MDT meeting with patient and carer to discuss plan of care</li> <li>• NT attendance at discharge care planning meeting</li> <li>• Liaise with JCM if care agency already involved to review whether they can continue to meet patient’s increasing level of need</li> </ul> <p><b>Advance care planning</b> discussions to include:</p> <ul style="list-style-type: none"> <li>• DNACPR status</li> <li>• Preferred place of care and death</li> </ul> <p><b>Reassessment of needs</b> including:</p> <ul style="list-style-type: none"> <li>• Psychological, spiritual and cultural needs</li> <li>• Comfort and wellbeing; symptom management, nutrition and hydration and personal care</li> <li>• Mobility, independence and personal goals</li> <li>• Moving and handling and equipment needs e.g. profiling bed</li> <li>• Consideration of anticipatory medication</li> <li>• Carers needs</li> <li>• CHC eligibility</li> <li>• Fast Track funding application considered and completed if condition rapidly deteriorating. Liaise with JCM re shared care plan if care agency involved; ensure care plan updated / shared</li> <li>• Liaise with residential care home staff re plan of care where appropriate</li> <li>• Referral for night care assessment via JCM</li> </ul> <p><b>Communication with MDT</b> regarding deteriorating condition, change in care needs and roles and responsibilities – discussion at GSF / daily review at cluster meetings. Update EPaCCS</p> <p>Consider <b>pre-bereavement support</b> and needs of carer / family</p> | <p>Contact / visits to be determined by assessed need, clinical judgement and patient’s preferences (this must not be repeated telephone contact)</p> <p>Recommended:<br/><b>1-4 visits daily</b></p> | <p>As above and level of care increase to:</p> <p>Provision of 2 night assessment to determine needs at night</p> <p>Based on assessment, patient will receive:</p> <ul style="list-style-type: none"> <li>• Night sitting service</li> <li>• Registered nurse visit as required</li> <li>• Allied roaming team visit</li> </ul> <p>Night care reviewed by night service every 2 weeks</p> | <p><b>Eligible for CHC / Fast Track funding</b></p> <p>JCM / Medical Social Worker to:</p> <ul style="list-style-type: none"> <li>• Establish NT’s capacity to provide visits e.g. 2 visits per day – including 1 registered nurse visit</li> <li>• Liaise with CHC to broker care package that cannot be met by the NT, including night care and consideration of existing care agency if involved</li> <li>• Complete holistic non-clinical assessment</li> <li>• Liaise with case manager / deputy to complete CHC care plan</li> </ul> <p>Shared care agreed with agency provider</p> |

## Care of the dying person (last days of life): Red - days

| Care outcome   | Case Manager's Responsibilities<br>(Registered Clinician) or delegated deputy  | Frequency of contact / face-to-face visits   | Night Care   | Medical Social Worker / Joint Care Manager (JCM) Continuing Health Care (CHC)   |
|--|--|--|--|---|
| <p>Care needs of the dying person are met in the last days of life</p> <p>Care is well coordinated</p> <p>Patient and carers / family are supported and involved</p> | <p><b>Recognition that the patient is in the last days of life:</b></p> <ul style="list-style-type: none"> <li>• Liaison with MDT and agreement that patient in last days of life</li> <li>• Sensitive communication with patient and carer / family re. deteriorating condition, support available, future care wishes and what to expect</li> <li>• Review of advance care planning wishes and preferences e.g. PPD</li> <li>• Consider support of a chaplain or other religious leader</li> <li>• DNACPR form available</li> <li>• Update EPaCCS</li> <li>• Provision of patient and carer information – offer <i>Care in the Last Days of Life</i> information leaflet to support discussions</li> </ul> <p><b>Review support needs / package of care</b></p> <ul style="list-style-type: none"> <li>• Review NT capacity to provide care</li> <li>• Inform JCM / care agency / residential care home if involved of any change in care needs and the plan of care</li> <li>• Night service must be informed that the patient has deteriorated in order for them to review care provided overnight</li> <li>• Urgent request for attendance at discharge care planning meeting / or Rapid Discharge Plan prioritised to enable discharge same day or within 24 hours</li> <li>• Daily review / discussion at cluster meetings</li> <li>• Involvement of patient and carer in decisions and delivery of care</li> <li>• Consideration of carer's needs and involvement in care</li> </ul> | <p>Contact/ visits to be determined by assessed need, clinical judgement and patient's preferences (this must not be telephone contact)</p> <p>Recommended:<br/><b>4 visits daily</b></p> <ul style="list-style-type: none"> <li>• Patient prioritised by NT - a minimum of 2 visits provided</li> <li>• Initial morning review visit by a registered nurse</li> <li>• Daily review of the plan of care</li> </ul> | <p>Night Service to prioritise patient for DN night carers</p> <p>Continuous assessment of need by Night Service</p> | <p><b>Eligible for CHC / Fast Track funding</b></p> <p>JCM / Medical Social Worker to:</p> <ul style="list-style-type: none"> <li>• Liaise with case manager / deputy to review team capacity to provide care to meet change in needs</li> <li>• Liaise with care agency re any changes to care package / plan</li> </ul> |

**Care of the dying person (last days of life): Red - days**

| Care outcome | Case Manager's Responsibilities<br>(Registered Clinician) or delegated deputy  | Frequency of contact / face-to-face visits | Night Care | Medical Social Worker / Joint Care Manager (JCM) Continuing Health Care (CHC) |
|--------------|--|--|------------|---|
|              | <p><b>Review of care needs:</b></p> <ul style="list-style-type: none"> <li>• Full reassessment of needs for the last days of life completed by senior clinician or delegated deputy</li> <li>• <b>Personalised Plan of Care for the Last Days of Life</b> in place and includes:                             <ul style="list-style-type: none"> <li>- Psychological and spiritual care</li> <li>- Symptom management</li> <li>- Nutrition and hydration</li> </ul> </li> <li>• Any changes to the plan of care shared with care agency / residential care home if involved</li> <li>• Provision of anticipatory medication and syringe driver equipment and continence and personal care supplies</li> </ul> |  |            |   |



## Care after death and bereavement: Gold Standards Framework - navy blue

| Care outcome  | Case Manager's Responsibilities<br>(Registered Clinician) or delegated deputy   | Frequency of contact / face-to-face visits   | Night Care   | Medical Social Worker / Joint Care Manager (JCM) Continuing Health Care (CHC) |
|---|---|--|--|---|
| Care after death needs met and bereavement support offered to carers / families | <p><b>Care after death:</b></p> <ul style="list-style-type: none"> <li>• Provide care after death, including verification of death (VoD) and psychological support</li> <li>• Consider any personal wishes</li> <li>• Offer bereavement information <i>When Someone Dies</i> and Leeds City Council information about registering a death</li> <li>• Complete care outcomes on EPaCCS / EPR – preferred place of death, actual place of death, VoD</li> </ul> <p><b>Bereavement support:</b></p> <ul style="list-style-type: none"> <li>• Inform all other agencies of patient death, including care agency nights, JCM – cancel planned visits</li> <li>• Offer bereavement support visits – coordinate with other agencies e.g. hospices re planned follow up</li> <li>• Ensure person is registered and create care plan / visit schedule</li> <li>• Sign post / refer where complex bereavement needs are identified</li> <li>• Reflect at cluster and GSF meeting</li> <li>• Consider team debrief / clinical supervision, including nights</li> </ul> | <p>Contact / visits to be determined by assessed need, clinical judgement and patient's preferences (this must not be telephone contact)</p> <p>Recommended:</p> <ul style="list-style-type: none"> <li>• Initial visit within 2-4 hours</li> <li>• Visit prior to funeral</li> <li>• Post funeral visit 7-10 days</li> <li>• Follow up visit 4-6 weeks</li> </ul> | <p>Provide:</p> <ul style="list-style-type: none"> <li>• Care after death, including verification of death</li> <li>• Psychological support</li> <li>• Bereavement information <i>When Someone Dies</i> information leaflet and Leeds City Council information about registering a death</li> </ul> <p>Inform neighbourhood team of patient death, verification and information provided</p> | Liaise with agency to cancel visits   |

### References:

*Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020*

*One chance to get it right: Improving people's experience of care in the last few days and hours of life (2014)*

*Priorities for care of the dying person (2014)* Published by the Leadership Alliance for the Care of Dying People

*End of life care for adults, NICE Quality Standard: QS13 (2013)*

*Care of dying adults in the last days of life, NICE Guideline: ng31 (2015)*