# End of life care prompts

## Care Homes: Guidance for inspectors

### What are end of life care prompts?

- The prompts are questions about the arrangements that should be in place if a service is caring for people who are coming to the end of their lives.
- The prompts are to help you think about how well a service recognises and responds to people’s individual needs.
- The list of prompts is not exhaustive. They should not be used as a set of direct questions to ask.

### When should I use these prompts?

- When planning fieldwork
- When writing hypotheses
- During fieldwork
- When analysing evidence
- When writing reports
- When registering a service
- During management reviews

### How should I use them?

- The prompts are there to support you to evaluate how well a service is meeting people’s end of life needs.
- Although there is only one standard about death and dying, the prompts will also help you to think about how evidence can be gathered to support your judgement in other outcome areas.
- The prompts can be used flexibly and in the way that helps you best at different times in your regulatory activity.
- **NOTE:** You should not use them as a checklist

### How do they relate to the KLORA?

- KLORA support us to make judgements about a service and are not replaced by these prompts.
- The prompts give more detailed support when assessing end of life care in social care services.

### What is the difference between

- Palliative Care is the active holistic care of people with advanced progressive illness, whereas end of life care is specifically concerned with the care of people who are dying.
### Palliative Care
- The goal is to achieve the best quality of life for people and their families focusing on effective management of pain and other symptoms and psychological, social and spiritual support.
- Many aspects of palliative care are also important earlier in the course of the illness together with other treatments.

### End of Life Care
- Helps all those with advanced, progressive, incurable illness to live as well as possible in the last stages of their lives.
- It enables the supportive and palliative care needs of both patient and family to be identified and met during the last phase of life and into bereavement.
- It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support.
- The phase ‘end of life’ ends in death.
- When it begins depends on the individual patient and professional perspectives.
- The beginning of this phase can be recognised by:
  - the person themselves
  - the health/social care professional/team responsible for the care of the person.
- In all cases the beginning of this phase will include a comprehensive assessment of supportive and palliative care needs. Consent to do this should come from the person or their representatives.

### Do care homes have to be registered to provide end of life care?
- No, all care homes can provide care to people at the end of their life. They should do this by following current good practice guidance.
- Some care homes may have a terminal illness (TI) category as part of their registration, but this is not a necessary requirement for a care home to accommodate people with palliative and end of life care needs.

### How do we work with the Healthcare Commission (now part of the Care Quality Commission) in regulating hospices?
- A very small number of hospices that are care homes are registered with the Healthcare Commission (now part of the Care Quality Commission). This is an anomaly that will be addressed when we move to CQC. In the meantime, there may be a rare circumstance where the Health Care Commission seek our advice to ensure:
  - the needs of the individual are met
  - the establishment is meeting statutory regulatory requirements.
- An establishment, registered with either commission, caring for an individual with palliative and or end of life care needs will be required to demonstrate its ability to meet the assessed need of that individual.

### How should a care home that provides end of life care, support the

- We would expect to see:
  - a relevant care assessment
  - further assessments by specialist palliative care services and other specialists, where needed. This may be part of a multi-disciplinary
| Are there specific end of life care tools which care homes must use | - We do not expect a care home to use a specific tool, such as the Gold Standard Framework (GSF) or Liverpool Care Pathway (LCP).  
- Some primary care trusts (PCTs) have developed their own tool for their locality and rolled it out into care homes.  
- We would expect to see evidence that a care home is familiar with the principles of end of life care and have adopted these principles and translated them into recorded plans of care and care delivery.  
- The LCP includes a record of the care to be provided in the last few days of life. It is acceptable for care homes to use a format like this, rather than the service user plan. |
|---|---|
| person? | approach. For example, GP, district nurse, occupational therapy, psychology, and specialists in dementia care  
- the least possible disruption to the individual and their family and those close to them. |
Choice of home

Key Outcomes
People are confident that the care home can support them. This is because there is an accurate assessment of their needs that they, or people close to them, have been involved in. This tells the home all about them, what they hope for and want to achieve, and the support they need.

End of life care outcomes
People feel that their end of life care needs will be met because staff have the right knowledge and skills to plan and deliver the care they need.

Questions to consider…

- Do staff have the knowledge and skills to identify individuals’ end of life care needs, for example, pain management, care of pressure areas, nutritional and hydration needs?
- Are there systems in place to access relevant specialists in palliative care, for example, GP, district nurse, or a specialist palliative care professional such as a Macmillan nurse?
- How are people who use services, or people close to them, involved in the assessment and planning of their end of life care needs, for example are their religious wishes being followed?
- Does the needs assessment show that pain, tissue viability, nutritional needs and other symptoms have been considered?
**Individual needs and choices**

**Key Outcomes**

People’s needs and goals are met. The home has a plan of care that the person, or someone close to them, has been involved in making. People are able to make decisions about their life, including their finances, with support if they need it. This is because staff promote their rights and choices

People have support to take risks to enable them to stay independent. This is because the staff have an appropriate information on which to base decisions.

**End of life care outcomes**

If people are approaching the end of their life, the care home will respect their choices and help them feel comfortable and secure. They and people close to them are reassured that their death will be handled with sensitivity, dignity and respect, and take account of their spiritual and cultural wishes.

**Questions to consider…**

- Are people able to continue to make choices in relation to their:
  - personal care and the level of support they want?
  - education and employment?
  - leisure activities?
  - daily routines?

- Have risk assessments been completed and agreed with the individual, or their representatives, to enable them to continue these functions and other daily routines for as long as possible?

- Are people given the opportunity to make choices and decisions about their preferred priorities of care (PPC) at the end of life?

- If there are ‘do not attempt to resuscitate’ (DNAR) decisions included in a person’s care plan, is there:
  - a policy in place
  - guidance and training for staff
  - a clear record and system for reviewing the decision
Lifestyle (YA)

Daily Life and Social Activities (OP)

**Key Outcomes**

Each person is treated as an individual and the care home is responsive to his or her race, culture, religion, age, disability, gender, including gender identity, and sexual orientation. They can take part in activities that are appropriate to their age and culture and are part of their local community. The care home supports people to follow personal interests and activities.

People are able to keep in touch with family, friends and representatives and the home supports them to have appropriate personal, family and sexual relationships.

People are as independent as they can be, lead their chosen lifestyle and have the opportunity to make the most of their abilities. Their dignity and rights are respected in their daily life. People have healthy, well-presented meals and snacks, at a time and place to suit them.

**End of life needs outcomes**

People at the end of their lives have cultural and spiritual networks they have identified as important to them.

**Questions to consider…**

- Does the home support people who use the service to have those who are important to them with them at the end of their life? For example the legal next of kin may not be the most important person to the resident. The resident’s wishes should be respected.

- Do the staff know about the specific nutritional and hydration needs for people who are at the end of their life? For example food and drinks should be available whenever the person wants them, not just at regular mealtimes.
### Key Outcomes

People receive personal support from staff in the way they prefer and want. Their physical and emotional health needs are met because the home has procedures in place that staff follow.

If people take medicine, they manage it themselves if they can. If they cannot manage their medicine, the care home supports them with it in a safe way.

### End of life care outcomes

If people are approaching the end of their life, the care home will respect their choices and help them feel comfortable and secure. They and people close to them are reassured that their death will be handled with sensitivity, dignity and respect, and take account of their spiritual and cultural wishes.

### Questions to consider…

- Does the review of care reflect the needs of the individual? Some people at the end of their life may need their care to be reviewed regularly, for example weekly, daily or in some cases within hours?
- Do the documents being used support end of life care planning? For example, the Liverpool care pathway (LCP), which includes a record of the care to be provided in the last few days of life.
- Does the manager know how to access an assessment for eligibility for NHS Continuing care funding?
- Does the manager know how to access the different services and specialist palliative care services that are available in the area? For example Macmillan nurses, hospice at home, or Marie Curie.
- Do the staff know how to seek appropriate specialist advice, for example, where there is an identified risk of malnutrition, has advice been sought from the community nurse, GP, dietician, speech therapist or palliative care service?
- Does the home enable people to stay at the home, if it is their choice, at the end of their life? Or are they transferred to other establishments, for example, hospital, or hospice?
- Does the home enable relatives and friends of the person to be with them at the end of their life?
- Does the home make sure that medicines are provided in a form that the individual can take, and is this reviewed at the end of life?
- Do the staff make sure medication and equipment for end of life care are readily available, for example syringe drivers (these may be provided by the PCT)?
- Do the staff use a ‘pain chart’ to record whether the person feels their medication has managed their pain?
- Do the staff arrange for supplies of medicines, including controlled drugs, for named individuals?
- Does the care home (nursing) hold a stock of prescription medicines, including controlled drugs? And if so, is there a current Home Office Licence to legally permit this (unless the care home is wholly or mainly maintained by charitable means when no licence is required)?
- Are medicines only given from ‘stock’ when there is written authorisation from a prescriber?
### Environment

#### Key Outcomes
People stay in a safe and well-maintained home that is homely, clean, comfortable, pleasant and hygienic.

#### End of life care outcomes
The home has the right specialist equipment and environment that supports end of life care.

#### Questions to consider...
- Does the environment allow for any required specialist equipment, such as a hospital bed or oxygen cylinder?
- Does the person’s private space support their privacy and dignity, and that of those who are close to them?
- Are appropriate hygiene and infection control practices in place? People who are ill and nearing the end of their lives are more prone to infections.
Staffing

Key Outcomes
People have safe and appropriate support as there are enough competent, qualified staff on duty at all times. They have confidence in the staff at the home because checks have been done to make sure that they are suitable.

People’s needs are met and they are supported because staff get the right training, supervision and support they need from their managers.

End of life care outcomes
People who are at the end of their life are supported by a staff team who are trained and experienced to meet their needs.

Questions to consider...
• Does the home provide enough staff to meet the needs of people at the end of their life? For example, care homes may need to increase the numbers of staff, especially at night if someone is close to the end of their life, to enable a member of staff to stay with the person.

• Are staff aware of their limitations in providing end of life care, and know when to contact other professionals for advice?

• Have staff received training in end of life care? For example:
  - knowledge of end of life care tools
  - knowledge of who to contact for advice
  - use of assessment tools for pain and tissue viability
  - how to manage pain and other symptoms
  - how to care for very ill people
  - supporting relatives and other residents (including where appropriate the bereavement process)
Conduct and management of the home (YA)

Management and Administration (OP)

**Key Outcomes**

People have confidence in the care home because it is run and managed appropriately.

People’s opinions are central to how the home develops and reviews their practice, as the home has appropriate ways of making sure they continue to get things right.

The environment is safe for people and staff because health and safety practices are carried out.

**End of life care outcomes**

People who are nearing the end of their life are confident their needs will be met in a well managed safe service.

**Questions to consider...**

- Does the manager ensure the care of people with end of life care needs reflects recent good practice and guidance? For example Department of Health, End of Life Care Programme, and National Council for palliative care.

- Is the manager aware that people nearing the end of their life are more at risk of falls and infections, and reflects this in the way they write and review risk assessments?

**Further guidance:**

Our guidance:

- Professional advice, for example:
  - Administration of medicines in care homes
  - Training care workers to safely administer medicines in care home
  - Management of controlled drugs

Policy and methodology> medication resources

- CQC Clinical triggers, for example:
  - Symptom management
  - Nutrition; Tissue viability
  - Continence
  - Dementia

Policy and methodology> documents for each care service>care homes with nursing

- Safeguarding Adults – Protocol and Guidance

End of life care prompts
Policy and methodology > concerns complaints and safeguarding > Safeguarding protocol guidance and forms

- National Minimum Standards (NMS) and regulations

Policy and methodology > documents for each care service

Other guidance:

- **NICE Guidance:** Supportive and Palliative Care (2004) (particularly chapter 8 which relates to generalist palliative care)

  www.nice.org.uk

- End of Life Care Programme publications. For example
  - **Advanced Care Planning** (2007)
  - **Introductory Guide to End of Life Care in Care Homes** (2006)

  www.endoflifecare.nhs.uk

- **National Council for Palliative Care**
  - Artificial Nutrition and Hydration
  - **Progress with Dementia:** addressing palliative care for people with dementia - including a set of ‘triggers’ to support the care of people with dementia who have end of life care needs.
  - **Changing Gear:** Guidelines for managing the last days of life in Adults).

  www.ncpc.org.uk

- **End of Life Care Programme**
  - The Liverpool Care Pathway, Preferred Priorities of Care and Advanced Care Planning
  - Changing Gear: Guidelines for managing the last days of life in adults
  - Support to people with a learning disability at the end of life
  - Preferred Priorities of Care
  - Introduction to End of Life Care in Care Homes
  - Building on Firm Foundations: end of life care in care homes

  www.endoflifecare.nhs.uk

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**End of life care prompts**
• Help the Aged
  - My Home Life: Quality of Life in Care Homes
    [www.helptheaged.org.uk/]

• Department of Health
  - Essence of Care – Benchmarks for the care environment
  - Mental capacity act 2005
  - Improving Nutritional Care – a joint action plan from the DH & Nutritional Summit Stakeholders
  - NHS Continuing healthcare and NHS funded nursing care
    [www.dh.gov.uk/publications]

• Resuscitation Council UK
  - Resuscitation guidelines 2005
    [http://www.resus.org.uk/siteIndx.htm]