



# Learning Disabilities Mortality Review (LeDeR) Programme: Fact Sheet 12

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## End of Life Planning (including advanced care planning) and End of Life care

### Key considerations for reviewers:

- Did the person have an Advanced Care Plan setting out their wishes and thoughts for the future as they approached the last year or so of their life, which set out:
  - What they want to happen.
  - What they don't want to happen.
  - Who will speak for them.
- Did the person have an end of life care plan which set out their preferred priorities for their end-of-life care including:
  - Where the person wanted to die (e.g. at home, hospital or hospice).
  - Who they wanted with them (e.g. family, support staff, chaplain, Iman).
  - How they wanted to be supported and whether any Advance Statement or Directive had been made.
- If available, were these care plans reviewed regularly in accordance with changing need?
- Did the person have a pain management plan?
- What reasonable adjustments had been made for the person's end-of-life care (e.g. easy read end-of-life information and care plans)?
- Was mental capacity assessed to gauge understanding of decisions made following the principles of the Mental Health Act 2005 (see Factsheet 1) and if appropriate, was an advocate appointed?
- Is it clear from the information available, how and when the person was actively involved in their end of life care and advanced care plan?

### Introduction

The Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD, 2013) reported that there were some difficulties identifying when the end of life was approaching for some people with learning disabilities and there were problems with coordinating care at the end of life. With a lack of planning and coordination often came poor-quality care in the final days of a person's life. Few people were found to have advanced care or end of life care plans.

Supporting people as they approach the end of their lives is vitally important. Key to this is:

- Recognising when people are approaching the end of their life.
- Knowing how to introduce discussion on planning care at the end of life using a sensitive, supporting and person-centred approach.
- Actively involving them in any decisions to be made, including chosen place of death.



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- Awareness of advanced care planning with access to adequate skilled staff and accessible resources to help in meeting individuals wishes, needs and preferences.
  - Coordination of end of life care and delivery of high quality services across different locations.
  - Access to skilled nursing care and practical support required for the last days of life.
  - Support for family carers or paid support staff caring for the person both during a person's illness and after their death.

### Key Principles

**Advanced Care Plan (ACP)** - Advanced Care Planning (ACP) is the process of discussing, recording and reviewing the preferences of a person about the type of care they would wish to receive and where they wish to be cared for, in case they lose capacity or are unable to express a preference in the future. An Advanced Care Planning discussion would include:

- The individual's concerns.
- Their important values or personal goals for care.
- Their understanding about their illness and prognosis.
- Their particular preferences for types of care or treatment that may be beneficial in the future.
- What they want to happen, what they would not want to happen, and who they would like to speak for them.

ACP may be instigated by either the individual or a care provider at any time not necessarily in the context of illness progression but may be at one of the following key points in the individual's life:

- Life changing event, e.g. the death of spouse or close friend or relative.
- Following a new diagnosis of life limiting condition e.g. cancer.
- If there is a significant shift in treatment focus where options for treatment require review.
- At an assessment of the individual's needs.
- If multiple hospital admissions have occurred.

**Palliative care** - Palliative care is that which is not preventative or curative but aimed at addressing symptoms associated with the condition (e.g. pain management). Palliative care for people with life-threatening/limiting illness provides holistic care from point of diagnosis through to death and beyond. It aims to manage distressing symptoms in the person, to address the physical, emotional, social, spiritual and practical needs of people and their families.

**End of life care plan** - End of life care plans usually cover care during the last days of life. They guide and document the care provided for people in the last days or hours of their life, incorporating the person's wishes as stated in their Advanced Care Plan.

**End of life care** - The General Medical Council defines end of life care as "*care that helps all those with advanced progressive, incurable illness to live as well as possible until they die*". End of life care is also applicable to those who approach the end of their life more suddenly (e.g. due to an unforeseen or accidental cause), where decisions may need to be made about treatment options including resuscitation. End of life care includes management of pain and other symptoms, as well as the provision of psychological and social support for patients and their families. Specialist end-of-life care is provided by multi-disciplinary teams.



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Whilst good quality end-of-life care should be available to everyone, place of residency, social class, gender, ethnicity, sexuality and disability have all been identified as affecting the nature and quality of end-of-life care received. Barriers faced by people with learning disabilities in accessing end of life care services include communication difficulties and professionals' lack of knowledge and experience of supporting people with learning disabilities.

### Recommendations for end of life care:

The Department of Health's *End of Life Care Strategy*, the Leadership Alliance for the Care of Dying People's (LACDP) *One Chance to Get it Right* and NICE guidelines include the following steps:

#### **Initial and careful identification of a person who may be approaching the end of their life:**

- Identification that a person may be at the end of their life must be clearly and sensitively communicated to individuals nearing end-of-life and their families/carers.
- When a person's health deteriorates an assessment must be made by a doctor who is competent in assessing whether these changes are potentially reversible or likely to result in the person's death. If changes in a person's health are deemed reversible, action must be taken in accordance with the person's wishes (e.g. Action/Care Plan, Advanced Decision) or in their best interest if previously established that they lack capacity to make the decision about treatment at that time (see Factsheet 2).
- Discussion about preferences for end-of-life care should be initiated with individuals and the people who are important to them. Mental capacity to make decisions should be assessed, together with the person's understanding of their situation (see Factsheet 2). Any concerns about care and treatment should also be addressed. If appropriate, the person must also be given support to understand information and communicate their wishes.
- Caution should be taken as not to label people as 'dying'. Care in the last days and hours of life should be viewed as a 'continuum', with the needs of the person being regularly reviewed.
- Information about individuals approaching end of life should be provided to out of hours services (e.g. through the locality wide register and/or the extension of the Gold Standards Framework or equivalent).

#### **Care planning:**

- The person's needs and preferences should be assessed. Decisions should be documented to avoid unnecessary repetition of discussions and ensure consistency of care.
- A care plan/advanced care plan should be agreed to reflect these preferences (e.g. where the person wants to die, whether they wish to make an Advanced Decision to refuse treatment should they lack capacity in the future; who they would like to be involved in discussions and decisions about their care; funeral arrangements).
- Care Plans should be person centred and reviewed regularly by a multidisciplinary team, the person and carers, as and when a person's condition or wishes change.
- Care Plans should include information on symptom control (e.g. pain relief) and how emotional, social, spiritual, cultural and religious needs will be supported.
- Plans should include information on feeding and hydration. Food and drink should be offered orally, as long as there is not risk of harm to health (e.g. risk of choking/aspirating food or drink) (see Factsheet 28).

#### **Co-ordination of care:**

- The person and their family/carers should always be informed as to who has responsibility for coordinating the person's treatment and care.
- It should be clear that the person and their family/carers are kept informed or consulted about their treatment and care.



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- If the person lacks capacity to make decisions, any decision made on behalf of the person must be in their best interest in accordance with the Mental Capacity Act (2005) (see Factsheet 2). All practical steps to help the person to make a decision should be taken when establishing whether the person has capacity.
- Professionals must respect a valid and applicable Advanced Decision. If the person made a Lasting Power of Attorney of Health and Welfare, the attorney should make a best interest decision on behalf of the person.
- Care plans should be easily available across care providers (e.g. social services, ambulance services, out-of-hour GPs).

### **Management of the last days of life:**

- End-of-life care providers should ensure that medical, nursing and personal care and carers' support services are available 24/7.
- Pain relieving and sedative medication should only be given for symptom relief and not prescribed as a matter of course. Particular caution should be taken in the use of syringe drivers to administer medication when a person is not able to take medication orally.
- Careful decision making about the withdrawal or start of potentially life-prolonging treatments must be exercised, especially during times when key individuals may not be available (i.e. night time, weekends and holiday periods). Healthcare professionals must carefully consider which decisions are imminent for the person's comfort and safety and which decisions can wait for a review of the person's condition by the senior doctor or appropriately appointed clinician who is responsible for the person's treatment and care.

### **Care after death:**

- All providers should have appropriate processes in place for verification and certification of death, and care after death, including viewing of the body and return of personal property.

### **Support for carers, both during a person's illness and after death:**

- Support for family members/carers must also be provided, both before and after a person's death.
- The needs of families and others identified as important to the person should be actively explored, respected and met as far as possible.
- The needs of carers should be appropriately assessed and recorded through a carer's assessment.

### **Children and Young People:**

At 16 years of age a young person can be presumed to have capacity to consent. However, a young person under 16 years may or may not have the capacity to consent, depending on their cognitive ability, level of understanding and maturity. An assessment of capacity to consent to treatment should be undertaken, ensuring an understanding of the implications of both receiving and not receiving treatment. A parent or adult who knows the child or young person well should also be involved in this assessment and any critical care choices which are made. The concerns and anxieties that parents or carers have regarding decisions around treatment and care, including starting or discontinuing invasive treatment such as tubes or cannulas (a tube used for the intravenous delivery or removal of fluid or oxygen) and ventilators to assist breathing, must also be taken into account and support given.

### **Deaths that must be reported to the coroner:**

- Identity of deceased unknown.
- Cause of death unknown.
- If the deceased person wasn't seen by the certifying doctor either after death or within 14 days before death.
- Sudden, unexpected, suspicious, violent (homicide, suicide, accidental) or unnatural deaths.



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- Deaths due to alcohol or drugs.
- Deaths due to self-neglect or neglect by others.
- Deaths due to industrial disease related to the deceased person's employment.
- Where the death may be due to abortion (i.e. doubtful stillbirth).
- Deaths during surgery or before recovery from effects of anaesthetic.
- Deaths within 24 hours of admission to hospital.
- Deaths during or shortly after detention in police or prison custody.
- Deaths of people subject to Deprivation of Liberty Safeguards (DoLS) (See Factsheet 3).

### Additional terms often associated with advanced care planning and end of life care:

- **Advanced Statement** - a statement that conveys a person's preferences, wishes, beliefs and statement values regarding their future care. The Statement provides a guide to those who may have to make decisions in the person's best interest if that person has lost the capacity to make a decision.
- **Advanced Decision/Directive to Refuse Treatment (ADRT)** - documented evidence of an individual's decision to refuse specific treatment made in advance when they have the mental capacity to do so (e.g. Do Not Resuscitate (DNR)). The decision only applies at some future time when the person lacks capacity to consent to or refuse specific treatment (see section 24 (1) of the Mental Capacity Act, 2005).
- **Best interest decisions** - decisions which are made on behalf of a person who lacks mental capacity, usually concerning care and treatment, or the stopping of treatment, carried out in the person's best interests (see Factsheet 2).
- **Care pathway** - anticipated care and treatment within an appropriate time frame which is written into a care plan and agreed by the individuals receiving the care, or advocate (if assessed to not have mental capacity) and a multidisciplinary team of professionals.
- **Children's hospice care** - children's hospice services provide specialist respite, emergency, palliative and end of life care for children with life limiting conditions, either in the setting of a purpose built hospice or within the child's own home. Children's hospice care teams bring together a range of professional skills and services under one roof and offer care and support to all family members. Care can be provided over a long period of time with regular short breaks and support for whole family. The service is often involved with the child and their carers from diagnosis to end-of-life.
- **Adult's hospice care** - adult's hospice services care for a person facing the end of their life and their family. Hospice care for adults focuses less on respite and more on end of life care and symptom management - the hospice service usually only becomes involved as health deteriorates. Care is provided in a range of settings including at home, in day care and in a hospice.
- **Independent Mental Capacity Advocate (IMCA)** - if a person who lacks capacity has no close family or friends to support mental capacity, an Independent Mental Capacity Advocate (IMCA) must be instructed. The IMCA must be consulted regarding decision making about medical treatment and if the individual they represent is due to stay in hospital longer than 28 days or a care home for longer than 8 weeks. The only exception for consulting the IMCA being when urgent decisions over health care and treatment are needed.
- **Lasting Power of Attorney (LPA)** - a statutory form of power of attorney created by the Mental Capacity Act 2005. Anyone who has the capacity to do so may choose a person (an 'attorney') to take decisions on their behalf if they subsequently lose capacity.
- **Terminal care** - recognition that the end of life is imminent, usually within 48 hours or less.



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## Summary of key points

A person likely to die within a 12 month period is considered to be approaching the end of life. The person's needs and preferences for treatment should be assessed and decisions documented in an Advanced Care Plan. End of life care plans usually cover care during the last days of life. They guide and document the care provided for people, incorporating the person's wishes as stated in their Advanced Care Plan.

## Additional sources of information

### Advanced care planning

- General Medical Council: [End of Life Care, Advance Care Planning](#)
- Gold Standards Framework and the Supportive Care Pathway: [Thinking Ahead - Advance Care Planning \(ACP\)](#)
- A Mullick, J Martin and L Sallnow: [An introduction to advance care planning in practice](#)
- NHS End of Life Care Programme - [Advance Care Planning Powerpoint presentation 2008](#)
- Together for short lives: [A Family Companion Factsheet 10: Care Planning in Advance](#)

### End of life/Palliative care

- ACT (2011): [Basic Symptom Control in Paediatric Palliative Care](#)
- General Medical Council guidance for doctors: [Treatment and care towards the end of life: good practice in decision making](#)
- Mencap: [Best Practice Guide to End of Life Care](#)
- NICE guidance for end of life care: [Care of Dying Adults in the Last Days of Life](#)
- Macmillan Cancer Support and Marie Curie Cancer Care: [End of life: A guide for people in the final stages of life, and their carers](#)
- Together for Short Lives: [Standards framework for children's palliative care](#)
- My End of Life Plan: Example of an accessible End of Life Plan available from [2gether.nhs.uk](#)
- Living with an illness I will die from: Toolkit of accessible resources/ available from Keele University at [aldhc.co.uk](#)

### Easy read information and books

The Books Beyond Words series (St George's Hospital Medical School) include a series of texts around death, dying, cancer and bereavement that are written in plain English:

- *'Getting on with Cancer'* (Donaghy et al, 2002)
- *'Am I going to die?'* (Hollins S and Tuffrey-Wijne)
- *'When Dad died'* (Hollins S and Sireling L)
- *'When Mum died'* (Hollins S and Sireling L)
- *'When somebody dies'* (Hollins S, Dowling S, Blackman N)
- *'We're Living Well but Dying Matters'* (accessible film produced by CHANGE available from [dying matters.org](#))



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### Care pathways for children, young people and adults

Care pathways	<p>Care pathways for children and young people (click on links):</p> <ul style="list-style-type: none"><li>• <i>Together for Short Lives</i> has developed <a href="#">A Core Care Pathway for Children with Life-limiting and Life-threatening Conditions</a></li><li>• The Department of Health's <a href="#">National Framework for Children and Young People's Continuing Care</a></li><li>• Gold Standards framework for children is underway.</li><li>• The Preferred Place of Care tool can be adapted for use in children's services.</li><li>• The National Institute for Health and Care Excellent (NICE) - guidance on end of life care for children and young people <a href="https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-pdf-1837568722885">https://www.nice.org.uk/guidance/ng61/resources/end-of-life-care-for-infants-children-and-young-people-with-lifelimiting-conditions-planning-and-management-pdf-1837568722885</a></li></ul>	<p>Care pathways for adults (click on links):</p> <ul style="list-style-type: none"><li>• Leadership Alliance for the Care of Dying People's (LACDP) <a href="#">One Chance to Get it Right</a> has now superseded the phased out Liverpool Care Pathway.</li><li>• <a href="#">Gold Standards Framework</a> (GSF) is a systematic, evidence based approach to optimising care for all patients approaching the end of life, delivered by generalist frontline care providers.</li><li>• <a href="#">Preferred Place of Care</a> (PPC) is a nationally recognised tool for all palliative care patients used to record patients and carer's wishes in relation to their care and ultimate place of death.</li></ul>
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