

Version: 3 FOI Status: <b>Public</b>	End of Life Care and Unexpected Death Policy Derbyshire County Council Adult Social Care	Originally issued: June 2006 Issued: August 2022 Review Due: August 2024 Author: Quality and Compliance
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## End of Life Care and Unexpected Death Procedure Derbyshire County Council Adult Social Care

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If you would like to make any comments, amendments, additions etc please email [ASCH.adultcare.policy@derbyshire.gov.uk](mailto:ASCH.adultcare.policy@derbyshire.gov.uk)

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## 1. Aim

The quality of care that individuals receive in their last days is just as important as the quality of life which they experience prior to this. The physical and emotional needs of service users must be met as they die, their comfort and wellbeing should be attended to, and their wishes respected.

This policy sets out a framework for how end of life should be planned and managed with the people using our services.

This policy has been produced in consultation with relevant medical professionals and incorporates guidance from:

[Ambitions for Palliative and End of Life Care \(2nd Edition\)](#)

This framework was created by the National Palliative and End of Life Care Partnership, May 2021. This framework presents an overarching vision that palliative and end of life care are a priority for us all. There are 6 ambitions set out in the document which give the building blocks for local health and social care leaders to use to build an accessible, responsive, effective and personal care offer needed at the end of life.

[NICE End of Life Care Quality Standard 2021](#)

This sets out 5 quality standards for adults who are approaching the end of their life, and their families and carers who support them.

The ['One Chance to Get it Right'](#) document (NHS England)

This document references the 5 priorities for care which should be the touchstone for every point of care for those in the last days and hours of life and their families – from frontline health and care staff to commissioners and regulators.

## 2. Advanced Care Planning

Advanced care planning is a process entered into by a person who wants to plan for their end-of-life care.

People with capacity can plan and make advanced decisions in anticipation of future loss of mental capacity, so these plans can be referred to when an individual is no longer able to actively contribute to the care planning process.

It is essential that conversations held with individuals, families, or representatives in relation to end of life care are handled sensitively, but allow those involved to have honest, informed and timely conversations.

This is a voluntary process, but all individuals, who have capacity, should be offered the opportunity to express their choices about care and treatment they receive

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towards the end of their life, or whether to refuse treatment in specific circumstances, so you can understand what matters most to them and record this.

The individual can set on record their choices however they wish, with the exception of resuscitation decisions which must be recorded on accepted documentation, once shared with us, these must be documented clearly and accurately on the personal support plan (PSP). This will need to be reviewed annually, or when a change is communicated, an individual can change any aspect at any point in time, provided they have capacity.

If an individual lacks capacity to make decisions about their end of life care, then a decision must be taken in their best interests, in consultation with family or friends and in accordance with the [Mental Capacity Act 2005](#). If there is a person with a registered lasting power of attorney for health and wellbeing, then the attorney should make decisions about the care a person receives at the end of their life.

Further guidance on how this decision should be made is provided in the [Mental Capacity Act Code of Practice](#).

As this is a voluntary process an individual can explain they do not want to engage in any planning process. This should be reviewed alongside the PSP when appropriate, or at the request of the individual.

All outcomes must be recorded in the individual’s PSP, including if an individual does not wish to discuss their future care or choices.

The Advanced Care Plan may include decisions such as:

**Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)**

This is a form containing a summary of personalised recommendations for an individual’s clinical care in emergency situations. It is completed by a healthcare professional such as a GP or nurse who has completed appropriate training. An example of this form can be found [here](#).

These recommendations may include what treatment should, or should not be given, and in what circumstances. The form will also include whether the individual is to be resuscitated should the situation arise. Where the person has made their wishes around CPR clear then this information must be easy to access by staff and medical professionals and referred to in the PSP. Where a CPR decision is documented on the ReSPECT form this accepted documentation and does constitute a DNACPR form.

In some cases, an individual will only have a **Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR)** form. This will have been issued if, following discussion and/or consideration by a GP or other medical professional, it has been decided that they are not to be resuscitated in the event that they stop breathing or their heart stops beating. It is best practice for DNACPR forms to be replaced by ReSPECT

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forms outlining the individual’s personal preferences for treatment and care, considering priorities for extending quantity of life vs prioritising comfort and quality of life.

It may be that an individual has previously completed an **Advanced Decision to Refuse Treatment (ADRT)** document. This must be in writing, signed and dated by the individual, when they have capacity, and witnessed.

Colleagues working within Derbyshire County Council’s directly provided registered services must not sign or witness any documentation relating to an individual’s choices for their end-of-life care.

These advanced decisions must be accurately recorded on the individuals PSP and easily accessible.

Any forms completed and signed must be kept available to be shared with medical professionals should an emergency situation arise.

**Other documentation that may support the completion of Advanced Care Planning for people receiving care:**

**Derbyshire Healthcare Plan**

People with complex health problems, a palliative diagnosis, or complex long-term conditions that require regular emergency support may have a Derbyshire Healthcare Plan in place. This is drawn up between the person or their representatives and a healthcare professional, to provide informed, seamless patient care out of hours. This information is stored on a database at Derbyshire Health United (DHU) and should be reviewed by the GP or other healthcare professional such as a community matron or advanced clinical practitioner (ACP) on an annual basis or more frequently where required to ensure the information is relevant.

**Lasting Power of Attorney for Health and/ or Welfare**

This is a legal document which allows someone to nominate another person/s to make decisions on their behalf after they lose mental capacity to make those decisions. A copy of this document or letter of confirmation from the Office of Public Guardian must be stored in the person’s electronic record.

**3. Recognising Dying**

If there is a noticeable change in an individual’s health, the [RESTORE2](#) form can be used to identify whether a person may be deteriorating or at risk of physical deterioration. Staff must be properly trained in taking observations in order to support the RESTORE2 process.

Competing the form and taking a complete set of physical observations will inform conversations with health professionals about what, if any, escalation is required.

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The form includes the National Early Warning Score (NEWS2) which promotes a standardised response to the assessment and management of unwell individuals.

The results are not a replacement for clinical judgement and should always be used with reference to the persons advanced care plan and any agreed limits of treatment.

Signs that a person could be reaching the end of their life include signs that may have gradual onset (and may initially be associated with normal physical observations), such as reduced periods of being awake/alert, reduced oral intake/interest in food or ability to swallow, reduced communication, becoming weaker and increasing personal care needs.

If you are concerned about the person or if one observation has changed significantly, always act on your concerns and seek advice from a competent clinical decision maker such as a GP, registered nurse or associated healthcare professional AHP.

The decision as to whether an individual is end of life / for palliative care must be made by a medical professional or senior healthcare practitioner such as an Advanced Clinical Practitioner.

#### 4. Care of the Dying

When an individual has been assessed by a medical or senior healthcare professional as moving towards the end of their life, an end-of-life care plan should be developed which will record the priorities and any goals of the individual and how they will be achieved, monitored and reviewed.

The plan is recorded within the individual's PSP and must be reviewed and updated, when necessary, this could be frequently during end-of-life care. It is likely that most aspects of the PSP will need to be updated during this time.

This is a plan for the present and the future and will be subject to continuous review and change. It must be developed with the individual and the people who are important to them. Guidance around end-of-life care planning can be found at [Appendix 1](#).

If the individual lacks capacity, a plan can be made on their behalf, which should involve for example, family, friends, carers and/or representatives and take account of any advanced care plans previously completed. The processes required by the [Mental Capacity Act \(2005\)](#) should be followed to ensure that the decisions made are in the best interest of the resident.

The plan should set out personalised care that takes account of the wishes and preferences of the individual and those people important to them, and includes food and drink, symptom control, psychological, spiritual, religious and social support, hygiene and privacy needs.

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[Appendix 2](#) outlines best practice for workers when supporting individuals at the end of life, in order to maximise their comfort

## **End of Life Pathway**

If an individual has been assessed by health professionals as being end-of-life or for palliative care, consideration should be given to whether the person meets the continuing healthcare criteria and specifically the fast track criteria.

## **Communication**

Good communication with people and their family/ friends is essential during this time. It is important that they have the information they need or wish for and have had the opportunity to express their wishes and choices, thoughts or concerns.

Communication must be sensitive and compassionate.

Staff should spend time listening and talking with the individual whenever possible, including whilst providing direct support. Staff providing support should refer any questions the person or their family have about the arrangements in place to their manager or healthcare professional if they do not have the knowledge to answer them directly.

Extreme care must be taken when supporting a person who is unconscious. Staff must be aware that an unconscious person may still be able to hear and be aware of the presence of someone else in the room and so care must be taken not to discuss the person's condition within the room.

Effective multidisciplinary and interagency working is essential to ensure care is provided in the best possible way to the individual, to support symptom management, support eating and drinking, and have their hygiene and dignity needs met.

## **5. Death of a Person**

### **A CQC notification must be completed in the event of a person's death.**

On discovery of an individual where death is suspected the following procedures are to be used:

- [Appendix 3](#) – residential setting
- [Appendix 4](#) – community setting

[Appendix 5](#) explains how to close the individual's electronic record

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## 6. Support and Visiting

Towards the end of life, relatives and friends should be encouraged to visit as often as possible and at any time, if this is what the individual wishes, or is felt to be in keeping with what they would have wished if they lack capacity.

Staff should respond to relatives and friends with compassion and offer emotional support, allowing people the chance to share their fears and anxieties with them. This is likely to help both staff and relatives.

Relatives should be offered meals and refreshments whilst they are sitting with the person. If there is a room available, this can be offered to a relative who may wish to stay with the person, a comfortable chair and a blanket should be offered. Staff should make sure that the relative is kept informed and up to date with the person's treatment and condition and facilitate discussion with the person's relevant healthcare professional if necessary.

If a relative wishes to become involved in caring for the dying person, staff will make every effort to incorporate this into the daily routine. For example, if a relative wishes to help support the person to eat a meal or help the person prepare for bed the relative will be made aware of the person's normal routine and will be encouraged to participate.

Within residential units' other residents may wish to share in the companionship of the person and it is important that they are not excluded. It is essential that they understand that death within an establishment can be shared and that they in turn will be supported and comforted where necessary.

## 7. Training and Support

Support will be provided for those staff caring for people that are at the end of their life. Staff must be able to discuss their feelings and experiences with managers or colleagues.

Staff may feel that by talking naturally or openly to a person about dying, that they are being insensitive to the situation. The person, however, needs to feel able to talk about and express any feelings they have about the end of their life and distress can be caused by not allowing people to discuss what is happening to them if this is what they would like.

Once the person passes away, managers should speak to staff about the important work they have done supporting and caring for the individual and enabling that person to die at home with dignity and respect. Support and supervision must also be made available, including, where appropriate, referral for staff to the in-house counselling service.

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<b>Authorisation and Approval History</b>
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**Author History**

Authored by John Boadle	June 2006
Approved by Kieran Hickey Assistant Director Adult Care	June 2006
Authorised by Policy and Procedure Group	June 2006

**Change History**

Version 1 June 2006 John Boadle	New Policy
Version 2 October 2017 Emma Benton	Change of name. Reviewed in line with Derbyshire Alliance Dashboard. Consultation with DCC home care and a DCC care home
Version 3 August 2022 Quality and Compliance	Review and update