

**Derbyshire Handbook of**

**Priorities for Care**  
**when a person is in the last**  
**days of life**

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**DERBYSHIRE ALLIANCE**  
**FOR END OF LIFE CARE**

**[www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)**

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In recent years there has been a major drive to ensure all dying patients and their relatives and carers receive a high standard of care. 'One Chance to get it Right' (June 2014), issued by the Leadership Alliance for Care of Dying People (LACDP) recommends that professionals change their approach to the dying patient, removing 'care pathways' for the last days of life and focussing on 5 'Priorities for Care'.

'End of Life' is difficult to define. A person may be described as approaching the end of their life when they are in their final years, months, weeks or days. The type of care required depends on what stage the person is at in their end of life journey. Within Derbyshire a 'toolkit' of documents has been collected, which contains guidance and documents for use at different stages of the journey. To access the toolkit use the link below.

This handbook offers guidance for professionals when a person is believed to be in the final **days or hours** of life. As with all clinical guidance it aims to support but does not replace clinical judgement.

Always remember the Specialist Palliative Care Team is available for advice, especially if symptom control and/or communication is difficult.

**Recognising that a patient may be dying  
neither hastens nor postpones death**

[www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)

## **Priorities for care in the last days of life**

Five priority areas for care have been defined. These priority areas are all considered of equal importance:

The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.

Sensitive communication takes place between staff and the person who is dying, and those identified as important to them.

The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

## **Guidance to support the recognition that a person may be dying**

### **Why do you consider the patient is dying within hours to days?**

What is this person's health like normally? Is this deterioration unexpected or a predictable consequence of a known illness?

Is there any treatable problem that has caused this deterioration?

What interventions have been tried and what was the response?

*OR (patients at Derby Teaching Hospitals Foundation Trust only) Has the patient been supported by the AMBER care bundle but failed to respond to active medical intervention?*

Would providing support with nutrition and/or hydration be likely to lead to long term improvement?

Is the person showing new physical signs suggesting that death may occur within hours, for example:

- taking hardly any food
- managing only sips of fluid
- having difficulty with oral medication
- becoming increasingly weak
- more time asleep than awake
- becoming unrousable
- the person believes he/she is dying

## **Who has been involved in recognising the patient may be dying?**

Recognising dying can be difficult. The decision that a patient is likely to die within hours to days should be made after a discussion between the **most senior doctors and nurses** caring for the patient. If there is uncertainty, further opinions may be sought. Some patients improve unexpectedly; the plan for care must then be reconsidered and explained to the patient, carers and professionals.

## **Making a personalised plan of care with the patient and family for the last days of life**

Identify (with patient if possible) who is important to share information with. If there is a wish that issues are not discussed this should be respected but channels of communication should remain open.

Establish contact details for carers, including information about when to contact individuals (e.g. at night).

Explain what you think is happening and the reasons why you think the patient is dying.

Discuss that the patient is likely to die in the next few hours to days (and the difficulty of making an accurate prognosis).

Discuss **the patient's priorities for their care** at this time, including if appropriate whether they are happy to be cared for where they are or whether they wish to be cared for elsewhere.

- Does the patient have an advance care plan or statement?
- Does the patient have an advance decision to refuse treatment?
- Is there a lasting power of attorney for health and welfare?
- Is there any expressed wish for organ tissue donation?

If the patient lacks capacity, according with the Mental Capacity Act: establish priorities for care that are in the patient's best interests.

Discuss that observations, investigations, interventions or treatments which do not enhance comfort, dignity and peace may be stopped if they are no longer benefitting the patient.

Ask if there are any spiritual, cultural or psychological issues that need addressing for the patient or family.

It may be important to discuss the possible benefits and burdens of oral or clinically assisted nutrition and hydration.

Ask if the patient has any physical symptoms to address.

Consider:

**pain**  
**shortness of breath**  
**nausea**  
**vomiting**  
**restlessness**  
**confusion**  
**urinary retention**  
**dry mouth**  
**respiratory secretions**

Consider reversible causes for these symptoms.

**Refer to guidelines for symptom control.**  
**([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk))**

**Seek advice from senior colleagues or the palliative care team if needed.**



## Communication

When a patient is dying, good communication is pivotal.

Talk with the patient and any significant others to assess what they already know. Information that was accurate at another time in this episode of care may not be accurate now that the patient is thought to be in the last hours or days of life.

Explain that death is expected in coming hours or days. The focus is now on ensuring comfort.

It is important that you check a person understands after you have talked with them.

As far as possible, all decisions leading to a change in care should be discussed with the patient or carer.

**The views of patients and carers must be listened to and documented; with the aim that all patients (if well enough), relatives or carers are able to take a full and active part in planning priorities for care.**

Access to age appropriate advice and information to support children or adolescents should be made available.

Irrespective of any prior discussions, ensure that patient and others involved in their care understand how care will be delivered. In the patient's own home this could include contact details for the district nursing team, palliative care team, out of hours services, GP, home loans, what to do in an emergency, oxygen supplies.

Regardless of care setting this may also include sensitive and timely identification of what to expect during the dying process and any preferred funeral arrangements.

Barriers that have the potential to prevent communication must be assessed and if necessary, action taken.

Consider:

- problems with hearing, vision, speech
- the need for an interpreter
- learning disabilities
- dementia
- neurological conditions and confusion

If a patient lacks capacity, act in accordance with the Mental Capacity Act to ensure care is given in the patient's best interests. Consider the support of an Independent Mental Capacity Advocate (IMCA). The relative or carer may know how specific signs indicate distress if the patient is unable to articulate their own concerns.

There may be a valid reason for not undertaking a conversation with the patient, for example:

- Patient requested not to be told bad news
- Patient is alone and you want to have this conversation when a relative or carer is present

Such reasons should be carefully documented and reviewed regularly.

Following difficult conversations about dying it may be appropriate to offer the patient and carer written information.

([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk))

**If a conversation about dying is deemed appropriate, remember, it can be a difficult conversation to have. Recognise your limitations and seek advice where appropriate. If you do not feel able to discuss dying with a patient and carer seek support from a senior colleague.**

## **Is the patient in their preferred place of care?**

If the person is not in their preferred place of care, this should be explored further, taking into consideration the views of carers. You should have a conversation with the patient and any significant others to assess their level of awareness and to explain to them options available to support their choice.

There may be a valid reason why a person's preference is not achieved; if so this should be recorded.

## **Give carers information about care setting, if appropriate**

Inform carers about any facilities available to them at this time. Remember information received verbally may not be retained. Consider having supportive written information about what is offered where you are working.

In a unit offering 24 hour care, this might include car parking, public transport, refreshments, cash machines, payphones, accommodation, chaplaincy support, access to a nurse call bell.

## **Assess medication**

### **Discontinue non-essential medication.**

All current medication should be assessed. If swallowing is or is likely to be a problem necessary oral drugs may be converted to alternative routes e.g. oral liquid, subcutaneous, transdermal.

Non-essential medication should be discontinued to ensure the patient is not troubled by taking unnecessary medication.

### **Ensure that medication in support of symptom management is available and administered by the most appropriate route.**

Ensure that equipment supporting continuous subcutaneous infusion (CSCI) of medication in support of symptom management is available where required. If medication is required to be given via a CSCI then obtain the appropriate equipment required & use according to local policy and procedure.

As required ('just in case', 'anticipatory'), subcutaneous medication should be prescribed for the symptoms which may develop in the last hours of life.

Refer to symptom management guidelines if needed.  
([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk))

Anticipatory prescribing will ensure minimal delay in responding to a symptom if or when it arises. Medicines for symptom control should only be given when needed, at the right time and just enough and no more than is needed to help control the symptom and titrated according to individual patient need.

## Discontinue inappropriate interventions

When death is expected healthcare professionals should aim to maximise comfort and avoid invasive, futile, potentially painful and unnecessary procedures/interventions being carried out when no clear benefit can be gained.

All decisions taken regarding interventions (i.e. to be continued, discontinued or commenced) must have been reviewed by the MDT and considered to be in the patient's best interest at this moment in time.

Today, is the patient gaining benefit from any of the following interventions?

- Routine blood tests
- Antibiotics
- IV Fluids & Medication
- PEG/J feeding
- Blood glucose monitoring
  - *may need to reduce frequency if continued*
- Recording of routine vital signs i.e. TPR/BP/O2

**If the patient has a cardiac defibrillator (ICD) contact the ICD/Pacing Clinic. Continuing cardiac defibrillation**

until the point of death can be distressing and confusing to relatives or carers when no clear benefit can be gained. All interventions must be considered to be in the patient's best interest. Consider contacting the patient's cardiologist if there are further questions.

Give information leaflet to patient/ relative or carer wherever appropriate.

(<http://www.arrhythmiaalliance.org.uk>patient information leaflet: CRT / ICD / S-ICD Patient Information)

**If the patient has equipment to support breathing (BiPAP, CPAP, Cough assist),** contact the respiratory or neurological team. Continuing the use of equipment to support breathing until the point of death can be distressing and confusing to relatives or carers when no clear benefit can be gained. All interventions must be considered to be in the patient's best interest.

**Does the patient or family have any specific wishes regarding their care leading up to and after death? (e.g. visiting needs, cultural needs, organ/tissue donation – more information may be found at [www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk))**

Specific requests should be highlighted and addressed as required; either now, at death or after death

If the patient is unable to have this conversation you may wish to discuss the patient's needs or wishes with their loved one. Consider the implications of any valid advance care plan.

Document specific requests to aid and inform other personnel who may become involved in the patient's care.

It may be necessary to identify local policy and procedure regarding organ donation so that action can be taken when required.

Access to age appropriate advice and information to support children/ adolescents at this time should be made available.

## **Spiritual needs**

Ensure the patient and their loved ones receive appropriate spiritual support - give them the opportunity to discuss what is important to them at this time including their wishes, feelings, faith, beliefs, and values. Tools for assessing spiritual needs are available ([www.derbyshire.eolcare.uk](http://www.derbyshire.eolcare.uk)).

Even if the patient has previously been asked about these issues and may indeed have a documented formal religious tradition or spiritual belief, a conversation to identify the patient's current spiritual/religious/ cultural needs should be undertaken.

If the patient is unable to have this conversation with you, you may wish to discuss the patient's needs or wishes with a carer. Consider the implications of any valid advance care plan.

Specific requests should be highlighted and addressed as required; either now, at death or after death.

Any specific needs must be documented to aid and inform other personnel who may become involved in the patient's care.

Ensure that where possible the names and contact details of religious / spiritual advisors are recorded.



## **Identify how loved ones are to be informed of a patient's death**

Professionals must have up-to-date contact information for loved ones.

When communicating information of a sensitive nature around the patient's deteriorating condition/ impending death it is vital that an appropriate person can be contacted at an appropriate time.

Some carers may be working, elderly or indeed not want to be contacted until the following day irrespective of the patient's condition.

Establish how a loved one wishes to be told of a patient's impending death. In some situations the next of kin may not be the most appropriate person to be contacted at the time of impending death. A list of people may be given or mobile numbers may be needed.

Irrespective of prior documentation the healthcare professional must revisit this issue regularly to ensure details are documented correctly and wishes have not changed.

**Ensure all other professionals are aware that the patient is believed to be dying**

Depending on where the patient is cared for, other teams will need to be kept informed.

The primary health care team should always be made aware of the patient's condition as the patient is registered under their care. They need to know that the focus of care has changed because other members of the family may be known to the practice and may seek support. The GP or other member of the primary healthcare team may want to visit the patient or carer.

In the community setting – remember just because the GP or District Nurse may already be aware that the patient is dying there are other staff involved in this patient's care who may need to be contacted, e.g. Receptionist, Palliative care team, Physiotherapist, OT care agency, Chaplaincy team, Marie Curie Nurse, Out of Hours Service, Pharmacist, Ambulance service.

For patients in secondary care, doctors should contact the GP practice and have a conversation where possible or leave a message or secure fax out of hours to inform the practice of the current change in the plan of care.

Outpatient services and transport may need cancelling.

## Nutrition

A reduced need for food is part of the normal dying process.

The patient should be supported to take food by mouth for as long as it is tolerated and safe to do so.

Recognising that a patient is dying does not preclude the use of clinically assisted (artificial) nutrition. For many patients the use of assisted nutrition will not be required; a blanket policy for giving assisted (artificial) nutrition is ethically indefensible and in the case of patients lacking capacity is prohibited under the Mental Capacity Act (2005).

A full assessment of the patient's needs for assisted nutrition is necessary and communication with the patient, where possible, and relative or carer is essential. All clinical decisions must be made in the patient's best interests.

If clinically assisted (artificial) nutrition is already in place please record route i.e. Naso-Gastric, PEG/PEJ. Consider whether assisted nutrition is still required, and whether a reduction in rate / volume of feed is now indicated.

Explain the plan of care to the patient where appropriate, and to the relative or carer.

## Fluids

A reduced need for fluids is part of the normal dying process.

The patient should be supported to take fluids by mouth for as long as it is tolerated and safe to do so. Symptoms of thirst / dry mouth do not always indicate dehydration but are often due to mouth breathing or medication.

**Good mouth care is essential.**

Recognising that a patient is dying does not preclude the use of clinically assisted (artificial) hydration. For many patients the use of assisted hydration will not be required; a blanket policy for either giving assisted hydration or for not giving assisted hydration, is ethically indefensible and in the case of patients lacking capacity is prohibited under the Mental Capacity Act (2005).

A full assessment of the patient's need for this intervention is required and communication with the patient, where possible, and relative or carer is essential. All clinical decisions must be made in the patient's best interests.

If clinically assisted hydration is already in place, please record route (IV, subcutaneous). If hydration support is in place consider whether it is still needed, or whether a reduction in rate / volume is now indicated. Consider use of subcutaneous route for administration.

Explain the plan of care to the patient where appropriate, and the relative or carer.



## Care and communication after death

### Last offices

Verification of death may be undertaken by any appropriately qualified professional. Local policy must be followed.

The patient is treated with respect and dignity whilst last offices are undertaken, according to local policy and procedure.

As far as possible, procedures following death must be carried out according to the patient's wishes. All specific religious/spiritual/ cultural rituals/ needs should be considered at this time. Be aware that wishes may vary according to place of death.

Patients and those present at the time of death must be afforded privacy, dignity and respect for their individual needs. This will extend to the care of their personal possessions whatever the care setting. Follow organisational policy for the management and storage of patient's valuables and belongings.

Universal precautions and local policy and procedures including infection risk should be adhered to.

Follow organisational policy for the management of ICDs or pacemakers if needed.

## **Practical instructions for a loved one after a patient has died**

Ensure the loved one can explain what they need to do next. Give them relevant written information in respect of practical or legal tasks following the patient's death.

Consider explaining about:

How and when death certificates may be issued and collected

How and when to contact the funeral director

When a pacemaker must be removed prior to cremation

If a post-mortem is required

If the coroner must be notified (eg case of industrial disease)

At this sad time retaining verbal information may be difficult and therefore the carer must be given written information to support the conversation that has taken place. Local Bereavement leaflets may be available.

See link for advice "What to do after death"

[http://www.adviceguide.org.uk/index/family\\_parent/family/what\\_to\\_do\\_after\\_a\\_death.htm](http://www.adviceguide.org.uk/index/family_parent/family/what_to_do_after_a_death.htm)

## **Bereavement support**

Bereavement support and local contact information should be made available.

In the event that there is an assessed risk of complicated grief, further contact or /and referral to specialist services may be necessary.

## **Informing professionals**

All personnel involved in the care of a patient must be informed of their death. This facilitates support for bereaved carers.

The patient's own GP (not just the out of hours team or GP on call) must be made aware of the patient's death. In an inpatient unit it would be appropriate for the team to contact the GP practice and have a conversation where possible or leave a message or secure fax out of hours to inform the GP practice of the patient's death.

Other organisations e.g. hospital, oncologist, palliative care team, hospice should be notified of the patient's death. Any outstanding appointments for the patient should be cancelled.

The patient's death is entered on the organisation's IT system.

## **Return of equipment and disposal of unused medication**

The timely and organised return of equipment is important. For some relatives, equipment may be regarded as a painful reminder of events that at this time are difficult to cope with. Return of equipment (especially large items) will enable relatives to re-organise their home. Returned equipment can be cleaned and made available for use by other patients who are dying.

The health or social care professional should arrange removal of those items that require cleaning or designated transport. Equipment such as syringe drivers may be removed by health care staff and dealt with according to local policy.

In some circumstances an urgent collection service exists.

Medication that is no longer required should be dealt with according to local policy so that the risk of inappropriate use is prevented.

Relatives or carers should be advised regarding any arrangements for removal of equipment.



