NHS
Oxford University Hospitals
NHS Foundation Trust

End of Life Care
What to expect when someone is dying in hospital

Information for families and caregivers

Care and support when it matters most

It can be helpful to understand what might happen when someone is nearing the end of their life. This information can help you to prepare and understand what you can do at this time. However, it is important to remember that not everyone follows a set pattern; each person's life and death are unique.

Death can sometimes occur suddenly or earlier than might have been expected. You may see some, none, or all of the signs of the last days and hours of life.

This leaflet explains what might happen in the last days and hours of life and gives examples of what you can do to support the dying person.

If you have any questions, please speak to any of the healthcare staff involved in the person's care. They will be able to help.

This leaflet also explains what needs to be done after someone dies.

Religious customs or preferences and spiritual care

The chaplaincy team are available to provide support and spiritual care for patients and families.

If there are any religious customs or preferences that need to be observed while the person is dying, or after death, please tell the doctor or nurse caring for them. They can make sure the wishes of the dying person are followed.

If requested, the Chaplaincy Team can offer advice on cultural and religious customs or preferences. They can also contact local or chosen ministers, priests or faith advisors for the dying person, for you, and other family members or visitors.

The Chaplaincy Team includes representative ministers from the major Christian and Muslim faiths. They work with faith advisors and trained volunteers from a wide range of faith backgrounds and traditions, to provide respectful and comprehensive spiritual care to patients and families. The Chaplaincy Team also offer support to people who do not follow any religious faith.

Please ask the staff to contact the Chaplaincy Team if you would like their support.

Tiredness and reduced energy

The dying person will have much less energy. This may mean they become less able to interact with others or to do things they previously found enjoyable. The person may appear withdrawn and show less interest in the world around them. They may not be able to talk as much and will tend to sleep more.

In the days or hours before death, the dying person is likely to respond less to voices and touch and may drift in and out of consciousness. Sometimes, quite unexpectedly, they might be more alert and talkative and even look as if they have improved. This may be a 'window of opportunity' to say anything you might feel you still need to say and to have some valuable time together.

What you can do:

- Remind the person who you are before you start what you want to say.
- Use gentle touch and provide reassurance. Tell them who you are, where they are, and what is happening around them.
- Even if the person is confused or in a coma and cannot respond to you, it can be very reassuring for them to hear familiar voices.
- Hearing is said to be the last sense to go, so assume that everything you say may be heard and understood, even if the person does not respond.
- Sometimes the sounds of familiar music, the radio or television programmes can help the person to relax.
- Also allow quiet and restful times, as sometimes peace and calm is what the person needs.

Loss of appetite

When a person is dying, they will often lose interest in food and drink. This is a normal part of dying. It is important not to press food or drink onto someone that no longer feels like eating or drinking.

It may become more difficult for the person to swallow, and they might not be able to swallow safely. If you notice the person is coughing when or after they swallow, this could be a sign they are unable to coordinate their swallowing movement safely, so food or drink may be going down the wrong way. This is called 'aspirating' and can cause uncomfortable symptoms. It might mean that the doctors and nurses caring for the person decide that they should not be given food or drink by mouth ('nil by mouth') for their safety and comfort.

It is not clear whether the use of clinically assisted nutrition and hydration (using 'drips' or feeding tubes) is helpful at the end of a person's life. These medical interventions may cause problems or discomfort for the dying person, for example pooling of fluid in the limbs or lungs.

The doctors and nurses looking after the person will decide whether they need clinically assisted nutrition and hydration. Please speak to the healthcare team if you have any questions and would like to discuss this.

Good mouth care is essential and will help relieve a dry mouth and the feeling of thirst. The nursing staff will use a range of products to keep the person's mouth clean and moist (such as mouthwashes, mouth moisturisers and lip balm). This can be an important way of helping the person to feel comfortable.

What you can do:

- Offer food and drink if it is wanted. Bring in things to eat and drink that the person might enjoy, but do not worry or press them to eat or drink if they don't want to.
- Help the person sit up which can help make swallowing safer.
- Tell the doctor or nurse if the person coughs when taking food or drink, so they can advise you what to do.
- Offer ice chips or sips of fluid to moisten their mouth.
- Bring in personal toiletries (such as the person's preferred toothbrush, toothpaste, mouthwash and lip balm).
- Ask the nursing staff to show you how you can help with mouth care.
- Wet the person's lips and mouth with a soft toothbrush dipped in water.
- Apply lip balm to protect their lips from dryness.

Change in bladder and bowel function

As energy levels drop and the person is less able to move around, they may no longer be able to get to the toilet or commode.

People at the end of life can lose control of their bladder and bowels. It is important to help the person remain as dignified and comfortable as possible.

If the person can control their bowels and can comfortably sit on a bedpan, then they will be helped with this.

It is vital that the person's skin is protected from becoming sore or damaged from contact with urine. The nursing staff may insert a catheter, which is a flexible tube placed into the bladder, allowing urine to drain into a collection bag. This helps to keep the person's skin clean and dry.

If the person doesn't want a catheter, or if it is not possible to insert one, then incontinence pads can be used to absorb urine. Regular checks will be carried out by nursing and support staff to make sure pads are changed when needed and the person's skin is well cared for.

What you can do:

- If the person can do so, encourage them to tell nursing staff when they need the toilet.
- Reassure the person that there is no need to be embarrassed if they have lost control of their bladder or bowels.
- Let the nursing staff know if you think the person's incontinence pad need to be checked or changed.

Pressure area care

When someone cannot move themselves in bed, they will need to be repositioned by the nursing staff every few hours. This is done to check that their skin is clean, is dry and to prevent pressure sores ('bedsores'), which can be painful.

The staff recognise the importance of being gentle when repositioning a person and of proceeding gently with reassurance and explanation.

If the person finds being repositioned painful, then an extra 'top up' of painkillers can be given beforehand to help reduce discomfort.

What you can do:

- Encourage the person to tell nursing staff straight away if their skin is becoming numb, itchy, or sore.
- Reassure the person and explain the need for repositioning.
- Remind the person that they can have extra painkillers before repositioning, if needed, as this can make being moved more comfortable.

Confusion or hallucinations

People who are dying often experience confusion, vivid dreams and hallucinations (delirium). You may notice the dying person talking to or seeing things or people that are not present. It is not unusual for them to see or hear people important to them who have already died. This is quite normal but can be unsettling for loved ones and you may be unsure how to respond.

Sometimes these dreams and hallucinations do not cause the dying person any distress, and can even be comforting, but sometimes they can be frightening or distressing. If they are distressing for the dying person, the doctor will be able to adjust their medication, helping the person feel calmer and more settled.

What you can do:

- Remind the person where they are and tell them who is with them and what is happening around them.
- Distraction may be helpful, as sometimes contradicting or trying to explain to the person does not help. Try not to challenge what they believe to be real.
- Bring familiar or comforting items in from their home. Sometimes having their own pillow or duvet, familiar objects or photographs, or having a certain radio station or music playing can help the person to feel more settled.
- Tell the doctor or nurse if the person is having vivid dreams or hallucinations, particularly if the person is distressed by them, as changes to their medication might be needed.

Restlessness and agitation

Restlessness and agitation are common at the end of life. Sometimes there is a clear cause (such as a pad that needs to be changed, pain or anxiety) which can be treated, but sometimes we cannot tell why a person is unsettled.

Sometimes restlessness can be the result of unresolved issues or worries. People who are dying often need to be reassured that things they were previously responsible for will be taken care of and that those they are leaving behind will be alright.

Sometimes the dying person is worried about something they have said or done in the past and hope that any wrong doing will be forgiven, hope that their life had meaning and that they will be remembered.

What you can do:

- Remind the person who you are, where they are and what is going on around them. Even if the dying person knows you well, they might not recognise you.
- Use a soft, gentle voice and reassuring touch.
- Tell the doctor or nurse if the person is restless. They will be able to assess for any possible causes and see if there are any medications that might be helpful.
- Bring in items from home that might be comforting.
- Be sensitive to any cues that might be a sign there is something the person wants to resolve before they die.
- When possible, stay calm yourself. A peaceful and relaxed environment can help to reassure the person and help them to feel settled.

Changes in breathing

You might notice a number of different changes in the person's breathing. It can become shallow and fast, or slow and laboured. There might also be gurgling or rattling sounds as the person breathes. Saliva and mucous, which are usually cleared by swallowing or coughing, collect at the back of the throat; air passing through these secretions causes this sound. This noisy breathing is not usually painful or distressing for the dying person, at this point they are likely to be unconscious.

Breathing can also become irregular. A particular pattern frequently seen at the end of life is called Cheyne-Stokes breathing. This involves very slow breathing or periods of time without a breath, followed by more rapid breathing or a much deeper breath. This is not uncomfortable or distressing for the dying person but might be unsettling to see or hear. It is a sign that death may be near.

What you can do:

- Tell the doctor or nurse if you are worried that the person's breathing has become more difficult, or you are concerned they are distressed.
- Speak calmly and use gentle, reassuring touch.
- Adjusting the head of the bed (mechanically or with pillows) or turning the person onto their side can sometimes be helpful. Ask the nurses to consider repositioning the person if you think it might help.
- If secretions are collecting in the mouth, ask the nurses to turn the person's head to the side so that gravity can help to drain them.
- When possible, stay calm yourself. A peaceful and relaxed environment can help to reassure the person and help them to feel settled.

Medication

Taking medication can use a lot of energy and effort, so the possible benefit of each medicine needs to be carefully reconsidered. When someone is dying, they often have difficulty taking medication by mouth as they are sleepy or lose their ability to swallow.

The medical team will reconsider the person's medications and stop any that are no longer of any benefit. Even medicines that have been taken for many years and have been important may be stopped toward the end of someone's life.

Medication used to help with comfort at the end of life can be given by a subcutaneous injection or infusion, through a small needle into the soft tissue under the skin.

If the person is likely to need repeated injections, a syringe driver might be used. This is a small battery-operated pump that delivers a subcutaneous infusion, so that medication can be delivered at a continuous, steady rate. Giving medication in this way can be more comfortable than repeated injections and can also help to avoid 'ups and downs' in symptom control. An infusion can take some hours to be fully effective. If the person is uncomfortable an additional top up injection can be given.

Medication often needed by people at the end of life:

- painkillers (used for pain and sometimes shortness of breath and cough)
- anti-sickness medication (used for nausea, vomiting or hiccups)
- relaxants (for restlessness, anxiety, or to help with sleep)
- anti-delirium medication (for hallucinations or confusion)
- medicines to dry up secretions (for wet or bubbly breathing).

Care after someone has died

What happens when the person dies?

It can be difficult to be sure if someone has died just by looking at them, particularly as their breathing may have become irregular, shallow, and slow. If you think the person has died, call the nurse using the call bell or go to the nurses' station.

A doctor or other healthcare professional will need to see the body and verify the death. Any equipment that was being used (such as a syringe driver) should be left in place until it has been recorded that death has taken place.

There is no rush to do anything. People react in different ways to the death of a loved one or person close to them. You might want to spend some time with the person to say goodbye or you may want to leave straight away.

We will do our best to support you to do whatever feels right for you. If you would like a member of the Chaplaincy Team to come and be with you, just ask.

When the person dies you may notice some physical changes (e.g., a person's face may relax, and they will have stopped breathing).

If, for religious or cultural reasons, the burial needs to happen quickly, the hospital Bereavement Service and Chaplaincy Team will be able to help.

Medical certificate

You will be phoned by a hospital-based Bereavement officer and/or Medical Examiner Officer. They will have reviewed the patient's medical notes and sent a report to the Medical Examiner. The Medical Examiner may call to ask if you have any concerns around the care or cause of death that is being offered. This is an opportunity to raise any concerns you may have prior to registering your family member's death.

The Medical Examiner will discuss a cause of death with the attending doctor, the doctor will then write the **medical certificate of cause of death (MCCD)**.

The patient's death may need to be reported to the coroner if the person has died from an industrial disease (e.g., caused by asbestos), or if there are any questions about their death. This might result in either a postmortem or an inquest (with or without a postmortem) to find out why the death occurred. In these circumstances, the coroner will provide the medical certificate of cause of death.

The hospital's Bereavement Service will forward the MCCD to the death registration service by email. This usually happens within a few days of the person's death (unless the coroner is involved). The Bereavement Service will contact the named next of kin to let you/ them know when an appointment can be made at the registration services.

If you are planning a cremation, a Cremation Form 4 will need to be completed by a doctor who has seen the patient before death.

Registering the death

Once the Bereavement Service has contacted you, please book an appointment with the Oxfordshire Registry Office, please telephone **0345 241 2489** (Monday to Friday). This must be done **within five days** unless the death has been referred to the coroner. If it has, you will need to wait for the coroner to give permission before you can register the death.

The appointment can be made by a relative, someone present at the death, or the person making the funeral arrangements.

The Registrar will tell you about the Tell Us Once service. This service helps reduce the number of telephone calls you need to make to tell people and organisations about the person's death. It also allows you to inform central and local government departments of the death very quickly; this can be helpful to avoid over-payment of benefits and pensions.

The registration service will give you a telephone number, website link and unique reference number for you to be able to access the Tell Us Once service after you have registered the death of your relative/ friend.

Arranging the funeral

If there is a pre-paid funeral plan it will usually include details of what the person wanted, as well as which funeral director to use. If the person left instructions for their funeral but there is not enough money available to carry out their wishes, you can make changes, as the instructions are not legally binding.

You (or the person arranging the funeral) can either make all the arrangements for organising the funeral, can ask funeral directors to do this for you or share the arrangements with them.

A list of funeral directors can be found online:
www.uk-funerals.co.uk/funeral-directors.html

Advice on arranging a funeral yourself is available from:

The Good Funeral Guide

Website: **www.goodfuneralguide.co.uk**

The Natural Death Centre

Website: **www.naturaldeath.org.uk**

Funerals can be costly. It is important not to sign a contract (or the arrangement form) with the funeral director until you are sure that you want to use their service and you know how the funeral will be paid for.

Further information

Further information about end of life care and support is available from Dying Matters:

Website: **www.dyingmatters.org**

Bereavement and support

After someone close to you has died, you may find it helpful to talk with someone outside your family and close friends. Your GP can provide information about bereavement support and counselling services.

You may also find the following organisations helpful:

Sobell House Bereavement Service

Website: **www.sobellhouse.org**
Tel: **01865 225878**
Email: **sobellbereavementservice@ouh.nhs.uk**

Katharine House Bereavement Service

Website: **www.khh.org.uk**
Tel: **01295 811866**
Email: **khhbereavement@ouh.nhs.uk**

SeeSaw (grief support for the young in Oxfordshire)

Website: **www.seesaw.org.uk**
Tel: **01865 744768**

CRUSE Bereavement Care

Website: **www.cruse.org.uk**
Tel: **01865 245398**
Email: **admin@oxfordcruse.org.uk**

Samaritans

Website: **www.samaritans.org**
Tel: **116 123**
Email: **jo@samaritans.org**

Let's Talk About Loss

Website: **https://letstalkaboutloss.org/**

WAY Widowed and Young – Bereavement Support UK

Website: **www.widowedandyoung.org.uk**
Tel: **0300 201 0051**

Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

Author: Developed by the OUH Specialist Palliative Care Teams
Adapted from the original 'What to expect as death approaches' by B Taylor (July 2017)

November 2022
Review: November 2025
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information

Leaflet reference number: OMI 80430