

End of Life Care **What to expect when** **someone is dying**

**Information for families
and caregivers**



**Care and support
when it matters most**

Introduction

This leaflet, which is for hospice, hospital and at home situations, explains what might happen in the last days and hours of someone's life. You may be given this leaflet at any point and not necessarily because a healthcare professional thinks that the person you care for is dying imminently. This leaflet explains what you might see when a person is dying; it gives ideas on how you can help and what to do after the person has died.

It can be useful to know what to expect when someone is close to dying. This can help you feel more prepared, but every person is different and not everyone will go through the same things.

Sometimes death can happen suddenly or earlier than expected. You may or may not notice some of the signs listed.

Sudden changes can feel scary or like a crisis. These can happen even when people anticipate a peaceful death. These changes can't always be predicted or stopped. If the person that you are caring for is at higher risk of this, the healthcare team will let you know and support you.

If you feel worried or unsure about anything, please talk to the healthcare team.

Tiredness and having less energy

When someone is dying, they often feel very tired and have much less energy. They may not want to talk or do things they used to enjoy. They might seem quiet and less interested in what's happening around them. They may sleep more and talk less.

In the last days or hours of life, they may not respond to voices or touch. They might drift in and out of sleep or seem unaware of what's going on. Sometimes they may suddenly seem more awake and talkative. This can be surprising, but it usually doesn't last long and is a normal part of dying.

What you can do:

- Say your name when you start talking to them.
- Use gentle touch and speak calmly to comfort them.
- Even if they seem confused or asleep hearing familiar voices, music, or sounds like the TV or radio can help them feel safe. Sometimes just your presence without speaking can be reassuring.
- Hearing is believed to be the last sense to wane so speak kindly and clearly even if they don't respond.
- Give them quiet time too as they may need peace and rest.

Loss of appetite

When someone is dying, they often stop wanting food or drink. This is normal. It's important not to push them to eat or drink if they don't want to, as this can be upsetting for both of you.

Swallowing may become harder. If the person coughs when eating or drinking, food or drink may be entering the airway (windpipe) or lungs. This is called aspiration and can make them feel uncomfortable. The healthcare team might suggest the person should stop eating or drinking to keep them safe and comfortable.

Using drips or feeding tubes at the end of life doesn't always help and can sometimes cause problems like swelling or discomfort. If you have questions, talk to the healthcare team.

Even if the person isn't eating or drinking, keeping their mouth clean and moist is very important. This can help with dryness and make them feel more comfortable. You can use mouth moisturisers or lip balm.

What you can do:

- Offer food or drink if they want it but don't worry if they say no. If they do want something to eat or drink, help them sit up to make swallowing easier.
- Give small sips of water or ice chips to help moisten their mouth.
- Tell the healthcare team if they cough while eating or drinking.
- Use a soft toothbrush, sponge, or cloth dipped in water or their favourite drink to clean and wet their mouth.
- Apply lip balm to keep their lips soft. If they are using oxygen, don't use petroleum-based lip balm — ask the healthcare team for advice.
- Ask the healthcare team to show you how to help with mouth care.

Change in bladder and bowel function

As someone gets weaker and moves around less, they may not be able to get to the toilet. It's important to help them stay clean, comfortable, and treated with dignity.

People near the end of life may lose control of their bladder or bowels. This is normal, and the healthcare team can help you manage it.

It's very important to keep the person's skin clean and dry to stop it from getting sore. Some people may need a catheter — a soft tube inserted into the bladder that drains into a bag. This helps keep their skin dry. If a catheter isn't used, special pads and other products can help. These should be checked and changed often to keep the person comfortable..

What you can do:

- Reassure the person that it's okay and nothing to be embarrassed about.
- Keep their skin clean and dry to help prevent soreness or pressure ulcers (also called bed sores).
- If you feel worried about managing this, particularly at night, talk to the healthcare team
- Let the healthcare team know if the person is constipated, not passing urine, or has become incontinent, so they can give advice.

Skin changes

It is normal for the skin to change when someone is dying because the body is slowing down and blood flow is reduced.

The skin may

- Feel cool, especially on the hands and feet.
- Look pale, patchy or mottled.
 - o On lighter skin, this may look blue or purple.
 - o On darker skin, it may look darker, purple, or brown. It is often easiest to see on the lips or inside the mouth.
- Become thin, dry or flaky.
- Swell in some areas.

Skin can also bruise or tear more easily and may not heal. These changes are usually not painful. If the skin looks sore, tell the healthcare team so they can help.

How you can help

- Use light blankets or soft socks to keep hands and feet warm.
- Apply moisturising cream to keep skin soft and prevent dryness.
- Handle the skin gently to avoid bruising or tears.
- Help the person change position frequently to avoid pressure sores (particularly on heels, hips, or lower back).
- Remove tight stockings and dress in loose clothing for comfort.
- Tell the healthcare team if the skin looks sore.

Pressure area care

When someone can't move themselves in bed, they need help to change position regularly. This keeps them comfortable and helps prevent pressure ulcers that can be painful.

If moving causes pain, the person can have extra pain relief before being repositioned.

What you can do:

- Encourage the person to tell the healthcare team if their skin feels numb, itchy, or sore.
- Explain why regular repositioning is important and reassure them.
- Remind them they can have extra pain relief before moving if needed.
- If you need advice on pain relief related to pressure area care or repositioning, talk to the healthcare team

Confusion or hallucinations

When someone is dying, they might become confused or have vivid dreams. They may hallucinate — they might talk to people who aren't there or see things that others can't see. Changes in behaviour, with confusion and sometimes hallucinations, might be referred to as delirium. This is quite common near the end of life. It can feel strange or upsetting to those around them but it's usually not scary for the person who is dying.

Sometimes these experiences can even be comforting. If the person seems upset or frightened, let the healthcare team know so they can help.

What can you do if the person seems upset or frightened:

- Gently remind the person where they are, who is with them and what is happening.
- Try not to argue or correct them — it might make them more upset. Instead, calmly change the subject or distract them.
- Give them familiar things like a blanket or photo or play music to help them feel safe.
- Tell the healthcare team if the person seems confused or is hallucinating, particularly if they appeared distressed.

Feeling restless or agitated

Some people become restless or unsettled when they are close to dying. This is quite common. Sometimes it's because they are uncomfortable or confused. Sometimes, we may not know the exact cause, but it does not necessarily mean they are in pain.

They might also feel this way because they have worries or things on their mind. Talking about these feelings or hearing kind words can help.

What you can do:

- Use gentle touch such as a hand hold and speak gently and calmly. Try to stay relaxed — this can help the person feel more peaceful.
- Give them familiar or comforting things like a favourite blanket or photo or play music.
- Let the healthcare team know if the person seems restless or upset. They can check for causes and find ways to help.

Changes in breathing

When someone is dying their breathing often changes. It might become fast and shallow, or slow and heavy. They might have long pauses between breaths followed by quicker breathing. These changes are normal and usually don't cause pain or distress for the person.

You might also hear gurgling or rattling sounds when they breathe. This happens when saliva or mucus builds up in the throat. Normally people clear this by swallowing or coughing, but someone who is dying may not be able to do that. The sound can be upsetting to hear but it usually doesn't bother the person.

Sometimes these secretions can leak from the nose or mouth. These can be clear or discoloured, even appearing blood-stained at times. This is not anything to be concerned about and can just be wiped away. Please ask a health care professional for advice if you are concerned.

What you can do:

- Raise the head of the bed or use pillows to help them breathe more easily.
- Gently turn their head to the side to help drain fluids from the mouth.
- If you're worried about their breathing or think they might be uncomfortable, talk to the healthcare team.
- In some circumstances changes in breathing may occur suddenly as someone is approaching death. Sudden changes in breathing may indicate that the person is dying. If you see this, try to stay calm and remain with them.

Medication

When someone is dying, taking medicine by mouth can be difficult and tiring. The healthcare team will look at all the medicines the person is taking and stop any that are no longer helpful — even ones they've taken for a long time. Some medicines are continued to help with symptoms and keep the person comfortable.

What happens if a person stops being able to swallow

New medicines may be available in hospital or supplied in the home that are given as an injection. These are called just in case or anticipatory medicines. They are usually given by a nurse, through a small needle or line under the skin.

If the person needs several doses of medicine, a syringe driver may be used. This is a small machine that gives medicine slowly and steadily through the skin. It can be more comfortable than giving many injections and helps keep symptoms under control. A nurse changes the syringe driver every day. It can take a few hours for the medicine to start working fully. If the person is still uncomfortable, they might need extra doses of medicine.

Medicines used at the end of life can help with:

- Pain or breathlessness.
- Feeling sick, vomiting or hiccups.
- Restlessness, worry or sleep.
- Confusion or hallucinations.
- Noisy breathing.

If the person needs extra doses often the healthcare team may need to check and adjust their medicine.

Religious customs and spiritual support

If in hospice or hospital

The chaplaincy team is available to support patients and visitors. They include faith leaders from many religions. They can also support people who don't follow a religion.

If you would like to speak to someone from the chaplaincy team, ask a member of staff to help you get in touch.

If there are any religious or cultural customs that are important to follow while the person is dying or after death, please tell the healthcare team so they can respect these wishes.

If a rapid burial is needed for religious or cultural reasons, let the healthcare team know as soon as possible.

If at home

If you are at home and would like spiritual support but don't have a faith leader to speak to, ask the palliative care team to help you find someone who can visit.

If a rapid burial is needed, you can get advice from the local Register Office or a funeral director.

Children

There are several resources for talking to children when someone they love is dying. Seesaw is a good place to start www.seesaw.org.uk. Involve children as much as you feel comfortable. They can visit in hospital and the hospices but there should be a trusted adult who can respond if they become upset. If you are their usual care giver and are personally affected by the situation, it is recommended you have another person available for your child. It is generally more helpful for the child's longer term psychological well-being if they are allowed to be involved rather than shielded from the situation.

Pets

In hospital

Pets usually cannot be brought into hospital for infection control reasons.

In a hospice

It may be possible for a pet to visit the hospice units, but this needs to be discussed with the ward staff at the time.

At home

If you have pets in the home, then it may be reassuring to have them around the bed. However, they should not be on the bed as claws can damage mattresses.

Looking after yourself

When you are caring for someone who is dying it is very easy to neglect your own needs. You need to eat, sleep and rest to provide care. Whether you are in hospital, hospice or at home, it helps to identify friends or family who can help you with shopping or getting meals. Others may sit with the person who is unwell so that you can have a break. If you are unable to take breaks or to eat, or your sleep is disturbed, please do talk with the nurses or medical team.

What happens after someone has died

If the person dies in hospice or hospital

When someone dies, you may notice changes such as their face relaxing and their breathing stopping. Sometimes it's hard to judge if breathing has stopped, especially if their breathing was slow or erratic before. Sometimes it will seem that breathing has stopped, and you will think the person has died, but then they take a sudden breath which can be surprising. The person dying will not be upset by this. If you think the person has died, press the call bell or go to the nurses' station. A healthcare professional will come to help.

An appropriate healthcare professional will need to verify that the person has died. This involves checking for signs of life (heart sounds, pulse, sounds of breathing). Any medical equipment like a syringe driver should be left in place until this is done.

There's no need to rush away after the person has died. You might want to stay, or you might prefer to leave quickly. The staff will support you and can ask the chaplaincy team to visit you.

If the person dies at home

When someone dies, you may notice changes such as their face relaxing and their breathing stopping. Sometimes it's hard to judge if breathing has stopped, especially if their breathing was slow or erratic before. Sometimes it will seem that breathing has stopped, and you will think the person has died, but then they take a sudden breath which can be surprising. The person dying will not be upset by this.

A healthcare professional will need to come and verify that the person has died. This involves checking for signs of life (heart sounds, pulse, sounds of breathing). Any medical equipment like a syringe driver should be left in place until this has been confirmed.

There's no need to rush. People react in different ways when someone close to them dies. You might want to stay with the person or prefer to leave the room. Do whatever feels right for you.

Who to call

- **During normal hours** if the patient was visited at home by the district nurses, please contact them so that they can organise for someone to verify the death. If the patient was not visited at home by the district nurses, you will need to contact the patient's GP surgery so that an appropriately trained healthcare professional can come and verify the death. **If the death takes place during the night**, you do not need to call until the following morning unless you want to.
- If you want a healthcare professional to visit during the night, if the patient was known to the district nurses, you can call the district nursing team via the Single Point of Access number. Alternatively, call 111. It is important to say the death was expected and if the person had a Do Not Attempt Resuscitation or ReSPECT form. They will send an appropriately trained healthcare professional to verify the death.
- Sometimes it can take a while for a healthcare professional to come to verify the death. Delays may feel hard for you and the healthcare professional will try to be with you as soon as they are able.

When to contact the funeral director

Before the person dies it might help to speak with a funeral director. You can let them know about any special wishes the person has or ask questions about what happens after death.

After the death has been verified by a healthcare professional you can arrange for the funeral director to collect the body. They usually come quickly, but there's no need to rush. If you want more time or are waiting for family or friends to arrive you can ask the funeral director to come later.

Most funeral directors offer a 24-hour service to move the body to a funeral home.

A list of funeral directors can be found at:

www.uk-funerals.co.uk/funeraldirectors.html

Getting a medical certificate of death (MCCD)

All deaths are reviewed by an NHS doctor called a Medical Examiner (ME). After someone dies, their next of kin will get a phone call from the ME. They will explain the cause of death and ask if you have any questions or concerns.

Once the paperwork is ready, the ME office will let you know so you can book an appointment to register the death.

You can find more information about the Medical Examiner system here:

www.england.nhs.uk/establishing-medical-examiner-system-nhs

Coroner referrals

Sometimes a death needs to be looked at more closely. This involves a coroner referral. It doesn't always mean there will be a post-mortem or an inquest. If this happens, the coroner's office will contact the next of kin directly.

More information about when a death is reported to a coroner:

www.gov.uk/after-a-death/when-a-death-is-reported-to-a-coroner

Registering the Death

The death must be registered within five working days after the paperwork is sent to the Registry Office.

A close relative or partner should register the death. If they are not available, someone who was there when the person died or the person arranging the funeral can do it instead.

To book an appointment with an **Oxfordshire Registry Office**:

Telephone - 0345 241 2489 (Monday to Friday)

Online - www.oxfordshire.gov.uk/residents/communities/births-deaths-and-ceremonies/deaths/registering-death

You will be able to register the death and obtain death certificates from their office. The Registry Office will tell you what you need to do when you contact them.

The registrar will also tell you about the 'Tell Us Once' service: www.gov.uk/after-a-death/organisations-you-need-to-contact-and-tell-us-once. This service helps reduce the number of telephone calls you need to make to tell people and organisations about the person's death.

Arranging for equipment or medication to be collected

Check the label on any equipment to find out who to call to arrange collection. Sometimes it can take a while for equipment to be picked up.

Any unused medicines should be taken to a local pharmacy so they can be safely disposed of.

Funeral Plans and Arrangements

If the person had a pre-paid funeral plan, it would usually include details about what they wanted and which funeral director to use.

If they left instructions but there isn't enough money to follow them exactly you can make changes. These instructions are not legally required so you can adjust them if needed.

You (or the person organising the funeral) can:

- Make all the arrangements yourself.
- Ask the funeral director to do everything.
- Or share the planning with the funeral director.

Advice on arranging a funeral is available from:

The Good Funeral Guide - www.goodfuneralguide.co.uk

The Natural Death Centre - www.naturaldeath.org.uk

Hospice UK - www.hospiceuk.org

For help with funeral costs there is information on the Government Funeral Expenses Payment website

www.gov.uk/funeral-payments

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**

Bereavement and support

What to do when someone dies: Step by Step

provides a step-by-step guide for what you might need to after someone has died including providing information on bereavement resources.

www.gov.uk/when-someone-dies

Feedback

Please tell us about your experience with the Palliative Care Community Services by scanning the QR code or following the link below.



Website: www.ouh.nhs.uk/services/departments/palliative-care/services/#feedback

Please raise any concerns with staff at the time. If you need to speak the Lead Nurse, you can write to

Lead Nurse for Palliative Care Sobell House

Churchill Hospital Old Road,

Oxford OX3 7LE

Or email: PalliativeCareHub@oxnet.nhs.uk

If staff are unable to resolve your concerns, please contact our Patient Advice and Liaison Service (PALS).

Telephone: **01865 221 473**

Email: PALSCH@ouh.nhs.uk

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: OUH Specialist Palliative Care Teams
August 2026
Review: August 2029
Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



Adapted from What to expect when dying in community and hospitals

Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

OXFORD HOSPITALS CHARITY (REGISTERED CHARITY NUMBER 1175809)

