



What to expect when someone is dying
Information for families and caregivers

Introduction

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. It also explains what needs to be done after someone dies.

If you have any questions, please speak to the doctor or nurse involved in the person's care. They will be able to help.

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

Death can sometimes occur suddenly or unexpectedly earlier than might have been expected. You may see some, none, or all of these signs in the last days and hours of life. Speak to the doctor or nurse if you have any questions about whether the person might die suddenly or sooner than expected.

Tiredness and reduced energy

The dying person will have much less energy. This may mean they become less able to interact with others or 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 The person may appear withdrawn and show less interest in the world around them.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 suddenly 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 them who you are before you speak.
- Use gentle touch and provide reassurance. Tell them who you are, where they are, and what is happening around them.
- Even if they are confused or in a coma and cannot respond to you, it can be very reassuring for the person to hear familiar voices.
- Remember that hearing is said to be the last sense to go, so assume that everything you say may be heard and understood even if they don't 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 are what the person needs.

Loss of appetite

When a person is dying, they will often lose interest in food and drink. This is because their body no longer needs fuel to keep it going. 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, as this can be upsetting for both them and you.

It can also become more difficult for the person to swallow and they may 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 distressing symptoms. It might mean that the doctor 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.

What you can do:

- Offer food and drink if it is wanted, but don't worry or press them to eat or drink if they don't want to.
- Tell the doctor or nurse if the person coughs when taking food or drink, so they can give advice.
- Offer ice chips or sips of fluid to moisten the mouth.
- Wet the lips and mouth with a soft toothbrush dipped in water.
- Apply lip balm to protect the 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. It is really important to help the person remain as dignified and comfortable as possible.

People who are at the end of life often lose control of their bladder and bowels. This is normal and the district nurse can advise how to manage this.

What you can do:

- Reassure the person that there is no need to be embarrassed if they have lost control of their bladder or bowels.
- Keep affected areas clean and dry to promote comfort and avoid pressure sores (also known as bedsores)
- Tell the doctor or nurse if the person is constipated or has become incontinent so they can give advice.

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 who are 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.
- Sometimes contradicting or trying to explain to the person does not help. If this happens, try not to challenge what they believe to be real; distraction can sometimes be helpful.
- 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 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 they are worried about something they have said or done in the past; that any wrong-doing will be forgiven; that their life had meaning and that they will be remembered.

What you can do:

- Even if the dying person knows you well, they might not recognise you – always introduce yourself and remind them who you are, where they are and what is going on around them.
- Use a soft gentle voice and reassuring touch.
- Be sensitive to any cues that might be a sign there is something the person wants to resolve before they die.
- 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.
- 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; it is air passing through these secretions that causes this sound. This noisy breathing is often not distressing for the dying person.

Breathing can also become very 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 or, 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:

- Try to remain calm - your calmness can help reassure the dying person.
- 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.

- If secretions are collecting in the mouth, gently turn the person's head to the side so gravity can help to drain them.
- 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.

Medication

Taking medication can use a lot of energy and effort and can cause side effects, so the possible benefits of each medicine needs to be carefully considered. When someone is dying, they often have difficulty taking medication by mouth. They might also be very sleepy, or lose the ability to swallow.

The medical team will give careful thought when they review 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 always been very important may be stopped.

Medication used to help with comfort at the end of life can be given by a subcutaneous injection or infusion. These are given 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.

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 distressed confusion)
- Medicines to reduce secretions (for noisy, rattly breathing sounds).

Care after someone has died

What happens when the person dies?

When the person dies, you may notice that their face suddenly relaxes. They will also have stopped breathing.

If the eyes are open, you can close them by gently holding the eyelids closed with your fingertips for 30 seconds. If this does not work, the funeral director can help with this. They will also be able to help close the mouth if it is open.

Who to call

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

A doctor or other appropriate 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 properly recorded that death has taken place.

- In normal working hours, you will need to contact the patient's GP surgery so that a doctor or appropriately trained nurse can come and verify the death.
- If the death takes place during the night, you do not need to contact the doctor until the following morning unless you want to.
- If you want a healthcare professional to visit during the night, you can call Hospital at Home if the person was known to their service. Alternatively, you can call 111. It is important to say if the death was **expected** and if the person had a **Do Not Attempt Resuscitation form**. They might send a doctor, appropriately trained nurse, or a paramedic to verify the death.

Religious customs or preferences

If there are any religious customs or preferences that need to be observed, please tell any doctor or nurse who is present so that they can respect your wishes and those of the person who has died.

If, for religious or cultural reasons, the burial needs to happen quickly, you can get advice from the local Register Office or a funeral director.

When to contact the funeral director

After the death has been verified, you can contact a **funeral director** to arrange for the body to

be collected. There is no rush to do this. The funeral director will often come within an hour of being contacted. If you want a little more time, or need to wait for family or friends to arrive, you can ask the funeral director if they could come a bit later. Funeral directors usually provide a 24-hr service to move the body to a funeral home.

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

Further information can be found in the section on 'Arranging a funeral' towards the end of this leaflet.

Arranging for equipment to be collected

Unfortunately, equipment cannot always be collected immediately. Speak to the healthcare professional who arranged its delivery (the occupational therapist or district nurse) so that they can arrange collection. Alternatively, you can call **NRS** yourself on **01869 225420**.

All unused medicines will need to be returned to a pharmacist for safe disposal.

Getting a medical certificate

After the death has been verified, a doctor will need to **certify** the death. This involves providing you with a **medical certificate of cause of death**.

Sometimes a GP will verify and certify the death at the same time, but if a district nurse or an out-of-hours doctor verifies the death, you will need to contact the person's GP to arrange to collect the medical certificate of cause of death.

If the person's regular GP is unavailable, or if the GP has questions about the death, it may need to be reported to the coroner. The death will also 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 an investigation to find out why the death occurred. In these circumstances, the coroner will provide the medical certificate of cause of death.

If you are planning a cremation, a second doctor has to complete an additional form before this can take place. This is called a confirmatory medical certificate for cremation. If you tell the GP who provides the medical certificate of cause of death that a cremation is planned, they will arrange for this form to be completed by a doctor from a different GP practice; this doctor might phone to ask you a few questions about the death.

Registering the death

When you get the medical certificate of cause of death, you will need to arrange an appointment with your local Register office to register the death. 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.

To book an appointment with the Oxfordshire Register Office, please telephone **0345 241 2489** (Monday to Friday). The appointment can be made by a relative, someone present at the death, or the person making the funeral arrangements.

You will need to take the medical certificate of cause of death with you, so that the Registrar can give you the Death Certificate.

The Registrar will also 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.

If you want to use this service, you will need to book a longer appointment for registering the death. You will also need to take with you:

- the person's National Insurance number
- their passport number (if they had one)
- their driving licence (if relevant)
- their vehicle registration number (if relevant)
- their 'Blue Badge' (if relevant)
- any concessionary bus-pass
- details of any benefits they were getting (e.g. state pension)
- the name and address of their next of kin
- the name and address of any surviving spouse or civil partner
- the name, address and contact details of the person or company dealing with their estate (this is their 'executor' or 'administrator')
- details of any public sector or armed forces pension schemes they were receiving or paying in to

It is also possible to use the Tell Us Once service at a later date, by telephone or online. The Registrar will give you the contact details and a unique reference number to use.

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 they have 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 yourself, or can ask funeral directors to do this for you, or could share the arrangements with them. The funeral itself can be a faith-based ceremony, have no religious element, or be something in-between.

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 also available from **Dying matters:** www.dyingmatters.org

Bereavement and support

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

Useful phone numbers

It can be helpful to keep these all in one place. Space has been provided here so you can add useful numbers.

District Nurse:

Funeral Director:

Register Office: 0345 241 2489

Feedback

If you would like to give feedback on this leaflet, we would appreciate hearing from you. You can write to: Community Team, Sobell House, Churchill Hospital, Old Rd, Oxford, OX3 7LE.

Or email: sobell.advice@nhs.net

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