



What to expect when
someone important
to you is dying



Bringing care home



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to you is dying

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About this booklet

If you are caring for someone who is in the last stages of life, or who may be soon, this booklet is for you.

It is designed to help prepare you for what to expect in the very last days and hours of a person's life.

The final days of life are precious days, often remembered in detail by those who live on, and the priority is to ensure a peaceful and comfortable death with the right level of support for you and the person you are caring for.

Symptoms and emotions in the final days are often similar whatever the underlying illness – whether it is cancer, heart disease, lung disease or any other chronic condition.

If you have been involved in care up until the final days, then you may want to stay involved or you may want to step back and let others perform the physical care. You are part of the caring team and your voice should always be heard, and decisions shared.



What happens when someone is dying?

You may wonder what the dying process involves – what actually happens in the very last days and hours of a person’s life?

This process is unique to every single person. It is not always possible to:

- Know for sure that a person is in the last days of life
- Predict exactly when a person will die
- Know exactly what changes the person you are caring for will experience when they are dying

There are certain bodily changes that signify a person is likely to be close to death. It is normal for these signs to come and go over a period of days, and if they do go, this does not usually mean that the person is recovering.

Some of these changes may be distressing, but the information below may reassure you that many of these changes are not unusual, and suggest how you can help or seek guidance. As a carer, if any of these signs do start to overwhelm or distress you, you may wish to take a break and leave the bedside for a period. It’s important to think about your own feelings as well as those of the person you are caring for.



Apetite

The person's appetite is likely to be very reduced.

They may no longer wish to eat or drink anything. This could be because they find the effort of eating or drinking to be too much. But it may also be because they have little or no need or desire for food or drink.

Eventually, the person will stop eating and drinking, and will not be able to swallow tablets. If a person stops eating or drinking because of their reduced appetite, this may be hard to accept, but it is a normal part of the dying process.

If they stop drinking, their mouth may look dry, but this does not always mean they are dehydrated.

It is normal for all dying people eventually to stop eating and drinking. If the person is conscious and they want something to eat or drink, you can offer sips, provided they can still swallow.

You can give some comfort to a person with a dry mouth by:

- offering a drink through a straw (or from a teaspoon or syringe)
- moistening the mouth with a damp sponge – special kinds of oral sponges are available for this purpose (the person may bite on this at first, but keep holding it, as they will let go)
- placing ice chips in the mouth
- applying lip balm



Breathing

The person's breathing may change.

As a person's body becomes less active in the final stages of life, they need less oxygen, and their breathing may become shallower. There may be long pauses between their breaths.

Sometimes the person's breathing may also make a noise, commonly known as "death rattle". This is likely to be because they are not able to re-absorb or swallow the normal fluids in their chest or throat, which can cause a rattling sound.

In the very last moments of life, the person's breathing pattern may change. Breaths may become much slower and quieter before they stop altogether. A change in the breathing pattern is a normal part of the dying process. If the person is anxious, their breath rate may increase a little.

The rattling sound may be upsetting to hear, but it does not seem to cause any distress to the dying person. It can be a bit like snoring – which affects those who hear it more than the person who is making the sound.

The person does not usually need extra oxygen at this stage. If the person is anxious, sitting with them so that they know you are there may help to reduce their anxiety.

Breathlessness can be frightening – a small fan and an open window can help.

If the breathing is very rattly, it may be helpful to change the person's position so that they are on their side if they agree or do not seem too disturbed by being moved. You can ask to be shown the best way to move the person – ask about sliding sheets.

The doctor or nurse may also suggest medication which may help to reduce the fluids in their chest and throat. This is not always needed, and it does not always make a difference.



Temperature

The person's skin may feel cold and change colour.

The person's hands, feet, ears and nose may feel cold to the touch (this is due to reduced circulation).

Occasionally, a person's hands or other parts of the body may swell a little.

Their skin may also become mottled and blue or patchy and uneven in colour. These changes are all normal parts of the dying process.

If the person's hands swell, please be assured that this is not usually painful.

It may be comforting to put gloves or socks on the person.

You do not need to warm them up – but doing so may help you to feel more comfortable.

Gentle massage may help – the nurses may show you how.



Sleep

The person may become much sleepier.

The person is likely to spend more time sleeping, and will often be drowsy even when they are awake.

They may also drift in and out of consciousness.

Some people become completely unconscious for a period of time before they die - this could be short, or as long as several days.

It is normal for a dying person to sleep more. They may generally become less interested in what is going on around them, and have less energy to take part, but this does not necessarily mean they are no longer hearing what you say to them. It is important to remember that, even when the person is or appears to be sleeping or resting, they may still be able to hear you.

Do not feel that you need to stop communicating with the person. You might want to carry on speaking quietly and calmly to them.

You could also try letting them know you are there in other ways. For instance: holding their hand, reading to them, or playing their favourite music.



Restlessness

The person may become more restless and agitated.

This may happen in the last few days of life, though the person may become more peaceful again before they die.

Sometimes they may appear confused and may not recognise familiar faces. They may hallucinate, and see or hear people or things that are not actually there – for instance, they may see pets or people who have died. Restlessness and agitation can be caused by many things. It may be manageable by quiet reassurance and the comfort of people like you who are close to the person, though it may still be distressing for you to see.

Agitation could also be caused by physical problems, like constipation or difficulty passing urine – ask the doctor or nurse caring for the person if you are concerned about this.

If the dying person does not recognise you, this may be distressing for you but it is not a sign that they feel differently about you. More likely, it is that they are unable



to clearly distinguish between what is real and what is not – especially if they are a bit sleepy and drifting in and out of full consciousness, rather like what can happen when we are half-awake or half-asleep. Simply sitting with the person may often help to calm them down. Keeping things as normal as possible may help comfort the person.

You can also talk to the doctor or nurse, as they can check if there is any treatable reason for this or may be able to offer medication to help settle the person's anxiety.

You can help by:

- speaking clearly and audibly to the person
- telling/reminding them who you are (and being prepared to do so repeatedly)
- keeping their surroundings calm with minimal changes in noise level
- trying not to correct them if they say something wrong, or insist on them getting things accurate, as this may be upsetting for you and for them.



Control

The person may lose control of their bladder or bowels.

This happens because the muscles in these areas relax and don't work as they did. They may also have fewer bowel movements as they eat less, and their urine may get darker as they drink less. This may be distressing to see, and you may worry that the person may feel embarrassed.

You can ask a nurse to help by showing you how to:

- keep the person clean and comfortable
- protect the bed

You can also ask the nurse or doctor for equipment that may be able to help with this, such as incontinence pads or a catheter (a long thin tube that can be put into the person's bladder to drain urine).



Eyes

The person's eyes may be closed.

It is important to know that in these final stages, the person may close their eyes often. At some point, they may not open them again. Their eyes may often be half open, which can be distressing to see.

As they may still be able to hear you, take the opportunity to say the things that are important to you both.



The person's final moments

Particularly in the last few minutes, the person's face muscles may relax and they may become very pale. Their jaw may drop and their eyes may become less clear. The person's breathing will eventually stop. Often, the person's body will completely relax.

Sometimes it can be difficult to identify the exact moment when the person died. There may be one or two last gasps a minute or so after what seemed like the last breath. However, you should note down the time as close as possible to the moment they died.

This is always a profound moment, even when death has been expected for days. You may suddenly feel overwhelmed with sadness; you may want to be alone, or you may want to ring family and friends. By this time you may be exhausted with the caring and the waiting, and the relief and finality of the moment of death can take you by surprise.



What happens after the person has died?

Once the person has died and you have noted the time of death, you may wish to respond in a way which is appropriate to you at the time. This could be by:

- Carrying out a particular ritual or ceremony, if there is one that is important to you or the person who has died, and your culture or beliefs;
- Simply sitting and being with the person

After this, there are practical steps you can take. For useful information on these, you could look at : **'What to do when someone dies: A practical guide'** from the Bereavement Advice Centre (available online). It covers the key steps you need to take, especially:

- Contacting a member of nursing or medical staff (if they died in a hospice or hospital), or their GP, if they died in their home or care home
- Registering the death (which must be done within 5 days)
- Arranging a funeral



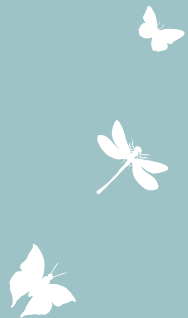
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