

Care and support when someone is believed to be in the last days of life



You have been given this booklet because the person you are visiting is very unwell and believed to be in the last days of their life. Knowing what to expect may help you cope at this time. This booklet describes some physical changes that may occur and the care we give when a person is thought to be dying.

Please ask if you have any concerns, no matter how small they might seem.

Recognising dying

It can be difficult to recognise when a person is entering their final days and hours. When a team who know a patient as well as possible believe they are dying - with hours or days to live - they will explain why they believe this to be the case.

They will always be willing to discuss your questions. Where possible, professionals will discuss changing physical health and decisions about care with their patient, but a person who is coming to the end of their life may be too unwell to communicate. The views of loved ones therefore are very valuable in planning and giving the best care to each individual.

Some people die very quickly with little warning and others become gradually less well over several days. Occasionally, people believed to be dying improve and stabilise. Each day, professionals will check to make sure the care being given is correct for the current situation. If there are any significant changes, they will talk to you about it.

Individual priorities for care

When it is believed a person is dying, the care team want to give bespoke, individualised care. You may have considered what is most important now. Please discuss this with your professionals. Below are suggestions about things that are often described as important.

Place of care

Some people have a clear idea of where they want to spend their last days. These thoughts may change over time. The care team will talk about what is practical for patients and carers and will do their best to accommodate individual wishes.

Religious and spiritual needs

There may be particular practices or prayers that are required. These may include asking a spiritual advisor to attend.

Food and drink

It is normal for a dying person to feel less like eating and drinking. We will help them to take food and fluids for as long as they are able to.

Changes to medication

When someone is believed to be dying, doctors will discuss whether medications remain helpful. If they are necessary, they may be given in a way that is easier for the patient, such as by an injection. A range of 'just in case' drugs will be prescribed that can be used if any troublesome symptoms occur.

Sometimes a 'syringe driver' (a small pump that delivers continuous medication by injection day and night) is used to help control distressing symptoms.

How a dying person might look

Every death is a unique experience. It is impossible to predict exactly how someone will look in their final hours, but there are certain common physical changes that you may notice.

Often a person becomes drowsy and begins to spend much of their time sleeping. Their skin may become pale and moist and their hands and feet feel cold. As they get more unwell, they will be awake less and have very little interest in their surroundings. This is part of the natural process and may be accompanied by feelings of tranquility.

Eventually they may become unconscious. For some, this period will be short, but for others it may last several days. Though unconscious, they may still be aware of your presence, your voice and your touch.

For most people, dying is a very peaceful process. There may be a gradual loss of consciousness followed by breathing changes, until breathing stops.

At such a sensitive time, you may wish to be involved in a practical way. We encourage those who feel able to take part in giving care, for example by giving drinks or moistening the mouth. The care team will support you to do as much or as little as is right for you.

Pain

A person who is in the last days of life may not be able to speak to tell us they are in pain. The care team will look out for signs such as grimacing (screwing up face), patients moving as if they are distressed and sweating.

If you are worried about pain, talk to your professional team who will help.

Restlessness

Sometimes a dying person becomes restless. This is usually caused by chemical changes in the body which affect the brain. Medications may therefore offer relief. Restlessness can also be caused by emotional distress. If this is the case, some people find it useful to talk to a trusted professional, close friend or spiritual/religious leader.

Incontinence

As a person gets closer to death, they may lose control of their bladder and bowels. Equipment such as pads or a catheter (a tube that goes into the bladder) can be helpful.

Breathing changes

When someone is dying, their breathing pattern may change.

Sometimes there are long gaps between breaths, or breathing may become fast and shallow.

Occasionally breathing may become noisy due to fluid collecting in the airways. Whilst this can be distressing to listen to, it does not usually cause the dying person distress (similar to the way that a person snoring is not disturbed as much as those around them). Staff will monitor things closely. A change of position may help, or medication may be used.

The final moments

For most people the final moments are peaceful.

Breathing becomes slower and more irregular with long gaps in between breaths.

Finally they stop breathing altogether. This might happen over a few minutes, but can be a longer process.

Often the person's body will relax completely and they may look very peaceful.

Afterwards

Following the death, you may feel very shocked, even if you felt well prepared.

In most cases there is no need to do anything straight away and if you want to, you can just stay with the person for a while.

A member of the care team will explain what to do next when you are ready.

If you are worried at any time that your loved one seems distressed or they have uncomfortable symptoms, please tell your care team

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