

What to expect in the last Weeks and Days of life

Information for patients, carers
and families

Thinking about the last weeks and days of life is hard but knowing what to expect may ease some of the worries you may be having.

Everyone's experiences are different but there are changes that often happen near to someone's death that may be signs the person is going to die soon.

Loss of Appetite

When someone is at the end of their life they may no longer wish to eat and drink, as their need for food and drink reduces. If they stop drinking and their mouth looks dry, this does not necessarily mean they are dehydrated.

It might be too much effort to eat and drink. If this is the case you can offer sips, ice chips or small bites, provided the person is conscious and can still swallow.

You can also help someone with a dry mouth by:

- Applying a water-based lip balm such as Oralieve or Beeswax as often as needed. Oralieve can be used alongside oxygen.
- Using a small headed soft bristled toothbrush and a mild non foaming toothpaste such as Oralieve or Biotene to clean the teeth.
- Moistening the mouth with water or a water-based mouth gel or spray such as Oralieve or Biotene regularly. Gels should be massaged into the soft tissues of the mouth using a soft toothbrush or circular brush.
- Mouth rinses and washes should ONLY be used to provide freshness if the person has the ability to swish and spit out the mouthwash.

Needing more sleep

When someone is at the end of their life, they are 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 periods of time before they die - this could be for a short period or as long as several days.

They may seem less interested in what is going on around them, and have less energy to take part, but this does not mean they can't hear you.

You can carry on speaking quietly and calmly to them. You could also try letting them know you are there in other ways, for instance by holding their hand, reading to them, or playing their favourite music.

Restlessness and agitation

Some people can become restless or agitated in the last few days of life. They will usually become calm again before they die.

They may appear confused and not recognise familiar faces, and even see or hear people or things that are not actually there - for instance, they may see pets or people who have died.

While this can be upsetting, it is very common, and it is not a sign that they feel differently about you. The restlessness can be caused by medicines or changes in the chemical balance of the brain, or as a result of drifting in and out of sleep so they are unable to clearly distinguish between what is real and what is not.

If they are agitated, often just sitting with the person can help to calm them down. You can also help by:

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

Agitation could also be a sign of constipation or difficulty passing urine. Ask the nursing or medical team if you have any concerns so they can rule out any underlying causes and if necessary, prescribe medicine.

Loss of consciousness

Many people lose consciousness near the end of life, this is very common. But they may still have some awareness of other people in the room. They may be able to hear what's being said or feel someone holding their hand. Keeping a calm presence and reducing lighting levels will enable the room to be peaceful and relaxed.

Changes to skin

The person's limbs, hands, feet, ears and nose may feel colder. This is because the blood circulation is slowing down.

People with lighter skin tones may look slightly blue or their skin can become mottled (have different coloured blotches or patches).

On people with darker skin tones, blue can be hard to see. It may be easier to see on their lips, nose, cheeks, ears, tongue, or the inside of

their mouth. Mottling is also harder to see on darker skin tones – skin might look darker than normal, purple or brownish in colour.

Toilet concerns

Some people may at this stage experience a loss of bladder and bowel control. This may happen earlier for some people. Your nursing team can offer support and advice should this happen. All main supermarkets sell products to help maintain dignity and hygiene if required.

Noisy breathing

Noisy breathing in the days before a person dies can be frightening but is completely normal. Breathing may become loud and noisy if mucus has built up in the airways. This is because the person isn't coughing or clearing their airways. Some people call this type of breathing the death rattle because it can happen in the last days or hours of life. This is not a medical emergency, but a normal part of the dying process.

It can be upsetting or worrying for those around the person to hear their noisy breathing. But it's unlikely to be painful or distressing for the person who is dying. Often they will be unconscious or won't be aware of it. Looking at the person's face may reassure you that they are not distressed, if the face appears relaxed it is likely that they are not distressed by the noisy breathing.

If you are concerned about noisy breathing, you can discuss this with your nursing team and medications may be prescribed alongside repositioning.

Sometimes it is not possible to alleviate the noisy breathing however the nurses will always ensure that your loved one is comfortable.

Shallow or irregular breathing

As the moment of death comes nearer, breathing usually slows down and becomes irregular. It might stop and then start again or there might be long pauses or stops between breaths. This is known as Cheyne-Stokes or agonal breathing. This can last for a short time or long time before breathing finally stops. Some people may switch between Cheyne-Stokes breathing and a more regular breathing pattern. This is not unusual.

Things you can do

- Sit with your loved one
- Hold their hand
- Moisten their mouth
- Play music / television quietly if these are things they enjoyed previously
- Read favourite books / poems / bible
- Look after yourself by eating and drinking regularly and getting some rest by sharing sitting with your loved one with family and friends who wish to do so.

Physical signs of dying

The following symptoms are often a sign that the person is about to die:

- They might close their eyes frequently or they might be half-open. Eyes may become less clear and may not focus on anything as they appear to look beyond you
- Facial muscles may relax, and the jaw can drop

- Skin can become very pale
- Breathing can alternate between loud rasping breaths and quiet breathing.
- Towards the end, dying people will often only breathe periodically, with an intake of breath followed by no breath for several seconds. This can be upsetting to witness as the person seems to stop breathing only to start again. There might be one or two last gasps a minute or so after what seemed like the last breath, before breathing eventually stops. This is all completely normal.

Moment of death

It's not always clear when the exact moment of death occurs.

When a person dies, those around them may notice that their face suddenly relaxes and looks peaceful. If the death isn't peaceful, it's unlikely that the person will have been aware of it. If anyone around the person finds it distressing, they can speak to a doctor, nurse, or bereavement counsellor.

The moment of someone's death is often very profound, even when you have expected it for a long time. You might want to talk to someone or call family and friends to let them know. You might prefer to be alone. You may find comfort from just sitting with your loved one. Do not be afraid to hold their hand and talk to them if you wish.

If you have been caring for the person you might feel exhausted, and the relief and finality of the moment of death can take you by surprise.

Some people feel overwhelmed with sadness, for others it can take days, weeks, or months to process how they feel.

Every person's experience of dying and bereavement is unique.



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