

What you can do to practically care for someone who is in their last days and hours of life.

This guidance is for carers and family members to know what to expect and how to make the experience as comfortable as possible. Your healthcare team will advise you on the medications that can help with controlling symptoms experienced at the end of life.

1. Breathlessness and cough

Breathlessness and cough can be a cause of agitation and distress and it can make it difficult to communicate. Don't expect the person to talk and give them time and space to respond. Reassure them that the unpleasant feeling will pass.

You can offer reassurance by talking calmly and opening a window to allow fresh air in.

If possible, sit the person up with pillows rather than lying flat as this can help the sensation of not being able to breathe.

Before someone dies their breathing often becomes noisy. Some people call this the 'death rattle'. Try not to be alarmed by this, it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing. There are medicines that can be given to help dry up secretions if it is a problem.

2. Pain

Some people may be in pain when they are dying. If they are less conscious they may grimace or groan to show this. There are medicines that can be given to ease pain.

Always check their positioning in bed to see if this can also help. They may be too weak to move and this can cause discomfort. Consider if they have any areas that are known to hurt, for example a bad back, and remember this when positioning them.

3. Going to the toilet

Towards the end of life, a person may lose control of their bladder and bowel. Even though we expect someone to go to the toilet less as they eat and drink less, contact the health care team that is looking after them if they have not passed any urine for 12 hours or more as it can be uncomfortable.

Keep the person comfortable by regularly washing them and changing pads if they are wet or soiled.

4. Agitation or restlessness

Some people can become agitated and appear distressed when they are dying. It can be frightening to look after someone who is restless. It's important to check if the cause is reversible like having a full bladder or bowel which can be reversed by using a catheter to drain the urine or medicines to open the bowels. Your health team can assess if this is necessary.

Check if their pad is wet to see if they are passing urine or if they are opening their bowels. If it's not either of these things, there are things you can do and give to help. Try to reassure the person by talking to them calmly and sitting with them. Touch can be effective in doing this too. There are also medicines that can be given to help settle and relax someone.

5. Feeling sick

Sometimes people can feel nauseated or sick when they are dying.

If vomiting, and unable to sit up, turn the person on their side to protect their airway. There are medicines that can be given to help relieve this.

6. Eating and drinking

As the body shuts down it no longer needs food and fluid to keep it going. When a person is dying they often lose their desire to eat or drink and finally their ability to swallow. They can lose weight rapidly. This is often difficult to accept because we often equate food with health and feeding people as an act of love. However, hunger and thirst are rarely a problem at the end of life.

Offer a variety of soft foods and sips of water with a teaspoon or straw for as long as the person is conscious (but allow them to refuse it). It's important not to force food or drink onto someone who no longer wants it. Remember to sit them up to avoid choking.

When a person is no longer able to swallow some people want them to have fluids via other routes like a drip, but at the end of life this offers little, if any, benefit. The body cannot process the fluid like a healthy body can and it can be harmful to artificially feed and hydrate. Risks include infection at the insertion site or in the blood, and fluid overload resulting in swelling or even breathing problems

7. Communication and environment

When approaching the end of life, people often sleep more than they are awake and may drift in and out of consciousness.

Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket for example, or piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting. This can reduce anxiety even when someone is unconscious. Even when they cannot respond, it is important to keep talking to them as they can most probably hear right up until they die.

8. Mouth Care

While people rarely complain of thirst at the end of life, a dry mouth can be a problem due to breathing mostly through their mouth.

It's important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. Regularly wet inside their mouth and around their teeth with a moistened toothbrush whether he or she is awake or has lost consciousness. Check for sore areas and white patches on the tongue, gums and inside the cheek which can be sore. If this happens tell the person's healthcare professionals as it can be treated easily.

9. Washing

Sometimes it may be too disruptive for the person to have a full wash. Just washing their hands and face and bottom can feel refreshing.

To give a bed bath, use two separate flannels, one for the face and top half of the body and one for the bottom half. Start at the top of the body, washing their face, arms, back, chest, and tummy. Next, wash their feet and legs. Finally, wash the area between their legs and their bottom. Rinse off soap completely to stop their skin feeling itchy. Dry their skin gently but thoroughly. Only expose the parts of the person's body that are being washed – you can cover the rest of their body with a towel. This helps to keep them warm and maintains their dignity.

10. Looking after yourself

Caring for a dying person can be exhausting both physically and emotionally. Take time out to eat and rest. Try to share the care with other people when possible and remember it is OK to leave the person's side to have a break.