What to expect when someone is in the last days and hours of life

Information for families and caregivers

HSC Health and Social Care

About this booklet

In this booklet we talk about caring for someone who is dying. You may be supporting someone at the end of their life. This can be a very emotional and challenging time.

We hope this booklet will help prepare you for what may happen in the final days and hours of the person's life, when death is expected and is not due to a sudden event.

You will also find some suggestions on how you can support the person who is dying.

Everyone is unique - therefore every person's death will be different. In most cases, there are common signs and changes that suggest that someone may be close to death, whatever their illness. This booklet will help explain them.

The person who is dying may have shared specific wishes for their care at end of life. This may have been through conversations or on a written plan. Please share these with the healthcare team, who will do their best to follow the person's wishes.

Also tell the healthcare team about things that are important to the person, such as family relationships, pets or any spiritual or cultural needs that staff should understand and respect.

This booklet may not cover all the questions you have. Please talk to the healthcare team if you have any other questions. We are here to support you.

Changes to expect in the last days of life

1. Tiredness and reduced energy

The person will have less energy and may be less able to talk or take part in things they previously enjoyed. They may show less interest in what is going on around them. They are also likely to spend more time sleeping and may often feel drowsy, even when awake.

As they come closer to death, they may drift in and out of consciousness. They may sometimes appear more awake or responsive for a short time. This up-and-down pattern is normal at this stage. It doesn't usually mean they are getting better. Some people become unconscious before they die; it can be a short time or as long as several days.

What you can do:

- When the person is sleeping or unconscious, they may still be able to hear you. You can keep talking to them. Try not to speak about sensitive things around the person.
- You could let them know you are there in other ways, such as holding their hand, reading to them, listening to their favourite music or TV programmes quietly.
- When they are in bed all the time, you can ask the team for advice on how to position the person comfortably. If you are caring for a loved one at home, ask your healthcare team about equipment that can help make them more comfortable, such as a different bed or a special mattress.

2. Loss of appetite and drinking less

As part of the dying process, it is normal for people to have little desire to eat and drink. This is a normal part of the dying process.

However, you may be able to provide food for comfort or tastes for pleasure. See page 4 for more advice on this.

During this time, some people can develop problems swallowing food and drink that can lead to coughing and choking.

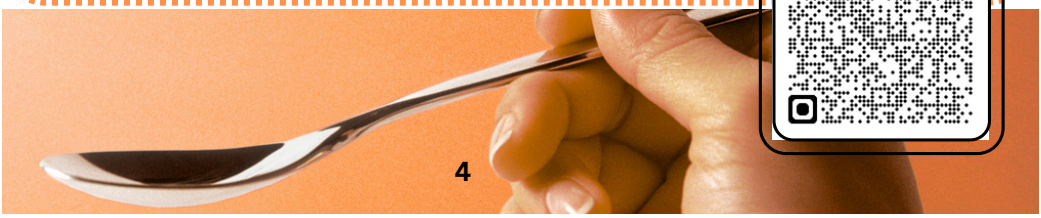
When a person is no longer able to drink and is expected to die within hours or days, giving fluids through a drip is unlikely to help them live longer or feel better.

Nursing staff or carers in the community will provide regular mouth care to ensure the person's mouth and lips are kept as clean and moist as possible. This is something you may want to assist with.

What you can do:

- If the person is alert and can swallow safely, you can offer small amounts of food or drink to keep their mouth moist. Try to ensure the person sits as upright as possible when they are eating or drinking. For some people a sports bottle or spouted beaker can help control the flow of the drink. For others, it may be easier to offer small amounts of food or drink using a teaspoon.
- To offer tastes for pleasure, dab a toothbrush into a favourite flavour such as tea, coffee or orange juice, shake off any excess liquid and tap gently onto the lips. Offer this as regularly as the person wants.
- Do not force them to eat or drink if they do not want to.
- If you notice coughing with food or drinks, tell the nurse or doctor so that they can advise you how to manage this.
- Ask the nursing team for advice about how you can help keep their mouth and lips moist and clean. Some people may require oxygen at end of life. If someone is on oxygen, check with a team member before using lip balms or moisturisers as some may not be suitable.

For more guidance, scan this QR code or click here



3. **Understanding End of Life medicines**

Some people need medicines in the last days of life to help relieve symptoms such as pain, breathlessness, nausea, restlessness or rattling or gurgling sounds when breathing. These medicines are often prescribed in advance, so they are there if needed. They are used to help keep the person comfortable. A doctor or nurse will review their medicines and stop any that are no longer needed.

As a person becomes drowsier, they may not be able to swallow medicines safely. If medicines are still needed, the team can give them in a different way. For example, they might use a battery syringe pump that delivers medicine steadily. A healthcare professional will explain the pump.

If the person experiences increased symptoms, “as required” injections can also be prescribed. Even if there is a syringe pump, extra medicine can be given to help control symptoms.

What you can do:

Tell the healthcare team

- if you think the person is in pain, uncomfortable or has any other symptoms that are distressing them.
- if you think the person struggles with swallowing medicines
- if you have any concerns about the pump

4. 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. They may have fewer bowel movements as they eat less, and their urine may get darker as they drink less.

Towards the end of life some people may lose control of their bladder and bowels as muscles relax, which is normal. Continence pads can help manage this and should be changed regularly to help keep skin clean.

The person may need a catheter, a tube that goes into the bladder and drains urine into a bag. The nurse can talk to you about this.

What you can do:

- Reassure them that there is no need to be embarrassed if they lose bladder or bowel control.
- It is important to help the person remain as dignified and comfortable as possible.
- Keeping the person's skin clean and dry can promote comfort and prevent breakdown of the skin. Talk to the nurse if you have concerns about this. The nurse can provide advice, equipment and continence products to help manage this.
- Let the healthcare team know if the person feels constipated or has not passed urine for 12 hours or more as this could cause them discomfort.

5. Changes in breathing

As a person's body becomes less active in the final stages of life, the way they breathe may change. Some people may feel breathless or short of breath in the last days of life; some may have experienced this throughout their illness. In general, in the last days of life their breathing may appear irregular or slower.

As death gets closer, the way a person breathes continues to change. Breaths may become much slower and shallower. There may be long pauses between breaths before they stop breathing altogether.

We all produce saliva in our mouth and mucus in our lungs normally. These fluids are called secretions. In the last days or hours of life, people may no longer be able to clear their throat or may be so relaxed that they don't feel the secretions. Therefore their breathing might be noisy or there may be a rattling sound. The "rattle" is simply air moving through secretions. It does not disturb the person but might sound disturbing to others.

When someone is dying, we rarely use suction as it can be uncomfortable and distressing for the person. Suction might irritate the airway and cause more secretions.

What you can do:

- Inform the team if you feel the person's breathing is causing them distress.
- Opening a window or using a small fan can be helpful if the person feels breathless.
- If the person is anxious, sitting with them may help reduce anxiety.
- A change of position can be helpful. Ask staff to show you how to adjust the pillows or bed head or change their position, if they are no longer able to do this.
- Ask for advice from staff to show you how to clear secretions from their mouth if this occurs; do not try this without getting advice.
- Discuss medications for secretions with nursing or medical staff.

6. Skin changes

As the person enters the last stages of life their skin may feel cold and change colour. Their hands, feet, ears or nose may feel cold to the touch. Their skin may look mottled and blue or patchy and uneven in colour. This is because their heart is sending blood to more vital parts of the body. Occasionally a person's hands or other parts of the body might swell a little. These are all normal parts of the dying process.

It is also necessary to regularly change a person's position to relieve pressure on particular parts of their skin. Your healthcare team will assist with this.

What you can do:

- It may be comforting to put on soft socks or an extra blanket.
- Gentle massage may be comforting; ask the team how to do this.
- Remove any tight rings.
- Talk to your health care team if changing the person's position causes any distress

7. Delirium

People who are dying may experience confusion, disorientation or difficulty concentrating (sometimes known as delirium). They may also experience vivid dreams or hallucinations. You may notice them talking to, or looking at, things or people that are not present. Sometimes they may not recognise you or their surroundings.

What you can do:

- Gently reassure them
- Sit alongside them, keeping things as normal as possible. Correcting or trying to reason with them often does not help.
- Keep surroundings calm. Avoid a lot of changes in noise and activity levels.
- Inform a team member if the person is becoming more confused or is having vivid dreams or hallucinations, particularly if you feel these are distressing them. The team may need to change the medicines.

8. Restlessness or agitation

Restlessness or agitation can come and go in the last few days of life. Sometimes the words “terminal agitation” or “terminal restlessness” are used to describe the muddled thinking or restless behaviours that can happen in someone close to death. Many things can cause this restlessness such as pain, discomfort, anxiety, constipation or difficulty passing urine. Sometimes no cause is found, and agitation may continue to “come and go”. Medication may help if the person is unsettled or distressed.

What you can do

- Keep surroundings calm. Have only a few people in the room at once. Avoid bright lights and a lot of noise.
- 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.
- Sitting quietly with the person may provide reassurance and comfort.
- Talk to the team, as they can assess if there is any cause they could treat.
- If you feel the person may have spiritual needs or worries, consider if you would like a chaplain or faith leader to visit.

9. Looking after yourself

We know how difficult it can be to watch someone you love and care for coming to the end of their life.

Serious illness affects the person experiencing the illness and those close to them. People cope in different ways. When you are supporting a loved one who is dying it is important that you look after yourself also.

Consider asking others to help with the caring role, to allow you time to eat and rest. It is okay to have a break e.g. to go for a short walk or meet friends. If you are working, speak with your employer to ensure they understand that you may need time off work to care for your loved one/friend.

If you are struggling with the caring role and do not have the support that you feel you need, please let the health care team know. They may be able to get you some extra support.

Some people feel they cannot be here at this time. That is ok. There is no blame or judgement. Please look after yourself and do what feels right for you.

10. Talking to children about death and dying

Children who are close to the person who is dying may have many questions. They will need support to help them deal with their loss. How to explain to them what is happening will depend on how old they are.

Very young children do not always understand illness. Older children may want to know more. Even very young children can tell when something is wrong. Try to be as open and honest as possible using words they will understand.

If you are finding this difficult, the social work staff or other members of the healthcare team can help you deal with children's questions, provide supportive, age-appropriate resources and advise how to support them through this.

It is also important to tell teachers what is happening in the family so that they can help support the child in the school environment.

11. When the person you are caring for dies

When the person is no longer breathing and their heart has stopped beating, they have died. This is a very personal moment for you. If the person is in hospital and there is no doctor or nurse present in the room when this happens, inform a member of the team. Once you have spoken with the staff, you do not have to do anything quickly. You may want to be alone, sit with the person for a while or you may want to ring family and friends. Do what is right for you.

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

- If the person dies at home, or in residential care, contact the District Nurse or GP to let them know. They will come out to verify the death before you contact the funeral director and explain what needs to happen next. If the death occurs in the evening, overnight or weekend, you can contact the District Nurse (if service available) or GP Out-of-Hours service who will help you.

  For GP out of hours scan this QR code visit NI Direct website (GP out of hours service) or click here

- If the person dies in hospital, a nursing home or a hospice, the nurse or doctor will verify the death, and the nursing staff will look after their care when you are ready for them to do this.

Please ask questions, discuss your concerns
and don't be afraid to ask for support.
The healthcare team is here to help you
at this difficult time.

Bereavement Support

There is support available for you if you have further questions, concerns or needs following the death of someone you know.

The Bereaved NI website offers information and support for people following a bereavement, or for those supporting someone who has been bereaved.
You can find the website at: https://bereaved.hscni.net/

For the website, scan this QR code or click here

Cruse has a bereavement support helpline (Monday to Friday): 0808 808 1677.

Version: August 2026 Review date: August 2029
This information is accurate at the time of printing.

This booklet was adapted from a Northern Health and Social Care Trust and Belfast Health and Social Care Trust resource. It has been endorsed regionally by the Palliative Care in Partnership Clinical Engagement Group.