



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

Information for families and caregivers

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. We appreciate this can be a very emotional and challenging time. We hope this booklet will help to 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 which suggest that someone may be close to death, whatever the illness. This booklet will help explain them.

The person who is dying may have shared specific wishes for their care at end of life. Please share these with the health care team who will do their best to follow the person's wishes.

Also tell the health care team about things that are important to the person, e.g. family relationships, pets or any spiritual or cultural needs that staff would need to understand and respect.

This booklet may not cover all the questions you have. Please talk to the healthcare team if you have any further questions. The team 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. Some people become completely unconscious before they die; this may be for a short time or as long as several days.

What you can do:



- Even when the person is sleeping or unconscious, they may still be able to hear you. You can keep talking to them. However, try not to speak about sensitive things around the person.
- You could let them know you are there in other ways e.g. 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 a member of the team for advice on how to position the person comfortably. If you are at home, you can ask about equipment that helps you care for the person and makes them more comfortable e.g. a different bed or special mattress.

2. Loss of appetite and drinking less

As part of the dying process, it is normal for people to lose their appetite. As the illness progresses and the body weakens, people often have little desire to eat and drink.

This is a normal part of the dying process. However, it is important to understand that you can still provide food for comfort with tastes for pleasure.

To offer tastes for pleasure, dab a toothbrush into a favourite flavour eg tea, coffee, orange juice, shake off any excess liquid and tap onto the lips. This can be offered regularly as desired.



When a person is no longer able to drink some people ask if fluids should be given through a drip or using other routes. However, when someone is expected to die within hours or days, this 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 they are as upright as possible. For some people a sports bottle/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.
- Do not force them to eat or drink if they do not want to.
- If they are coughing with food or drinks, it is important to 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. If the person is on oxygen (not everyone requires oxygen at end of life), check with a team member before using lip balms or moisturisers as some may not be suitable.



3. Unable to swallow medicines/liquids

As the person becomes drowsier, they may no longer be able to swallow their medications.

A doctor or nurse will review their medications and stop any that are no longer needed. Any medications the person still needs can be given in a different way. This could be done by using a small battery-operated syringe pump which delivers medication at a steady rate over 24 hours; you should be given a booklet to explain this.

“As required” injections will also be prescribed which means that if the person experiences increased pain or other symptoms despite the use of the syringe pump, they can be given extra medication to help control these symptoms.

What you can do:



- Tell the health care team if you think the person is no longer able to swallow their medications safely.
- Let the healthcare team know if you think the person is in pain, uncomfortable or has any other symptoms that are distressing them.



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.

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 have lost control of their bladder or bowel.
- It is important to help the person remain as dignified and comfortable as possible.
- Keep the person's skin clean and dry to promote comfort and prevent breakdown of the skin.
- If at home, ask the district nurse for advice, equipment and incontinence products to manage this.
- Let the health care 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.



Someone in the last days/hours of life is less able to clear their secretions (fluids that everyone has in their mouth and lungs e.g. saliva or mucus). Therefore, their breathing may sound noisy or there may be a rattling sound. The “rattle” is simply air moving through these secretions. It doesn't disturb the person, more those around them. We know that the person is often so deeply unconscious and relaxed that they do not feel the need to clear their throat.

When someone is dying, we rarely use suction as it can be uncomfortable and distressing for the person and the irritation can cause a further build-up of secretions.

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.

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/ 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.

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.



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. Their medications may need to be changed or they may need medication to relieve distress.

8. Restlessness or agitation

Restlessness or agitation can come and go in the last few days of life. You may hear the words “terminal agitation” or “terminal restlessness” being used. These terms just describe the muddled thinking or restless behaviours that sometimes happen in someone close to death. This restlessness can be caused by many things e.g. pain or discomfort, anxiety, constipation or difficulty passing urine. Sometimes no cause is found, and agitation may continue to “come and go”. If the person is unsettled or distressed, medication can help.



What you can do

- Keep surroundings calm by not having too many 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 reason they could treat.
- If you feel the person may have spiritual worries or needs, 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 more than the person with the illness; it can affect those important to them as well. People cope in different ways. When you are supporting a loved one who is dying it is important that you look after yourself also.

This might mean 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. It might also mean discussing your circumstances 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 as they may be able to get you some extra support. Some people may not feel that they are able to be present at this difficult time. There is no expectation or judgement to be made if this is the case. You must look after yourself and do what is 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 and 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 and older children may want to know more. Even very young children can tell when something is wrong, so 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 health care 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 also.

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 that need to be observed, please tell any 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. They will also explain what needs to happen next.
- 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.

At any time, please ask questions, discuss your concerns and don't be afraid to ask for support.

The health care team is here to help you at this difficult time.

Bereavement Support

There is support available for those who have experienced bereavement. People may have further questions, concerns or needs following the death of someone they 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/>

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



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