

Supporting care in the last days and hours of life

Family / Carer(s) Information

The healthcare team will have explained to you that there has been a change in your family member or friend's condition. They believe that the person you care about is now dying and in the last days or hours of life. The person and their care will be reviewed regularly.

You may like to be involved in elements of their care at this time, and the staff will talk to you about how you can help. This information sheet is to help you understand what to expect.

If you need more information or support, or do not agree with something, please ask the healthcare team. They are there to support you.

Comfort

Comfort is very important, please let the staff know if you feel the person is not comfortable. You can support the care given to your family member or friend in important ways such as spending time with them, sharing memories, bringing news of family and friends, or simply holding their hand.

Treatment and medications

Medications and tests that are not helpful may be stopped and new medicines to help manage symptoms will be prescribed. Medications for symptom control will only be given when needed. If the person cannot swallow medications they require, a small pump called a syringe driver may be used to give a continuous infusion under their skin.

Food and drink

Your family member or friend will be supported to eat and drink as long as possible, however, a loss of interest in, and a reduced need for food and solids is normal.

This can be hard to accept, even when you know the person is dying. Good mouth care is very important at this time and the nurses may ask if you would like to help with this care.

Spiritual, cultural and emotional care

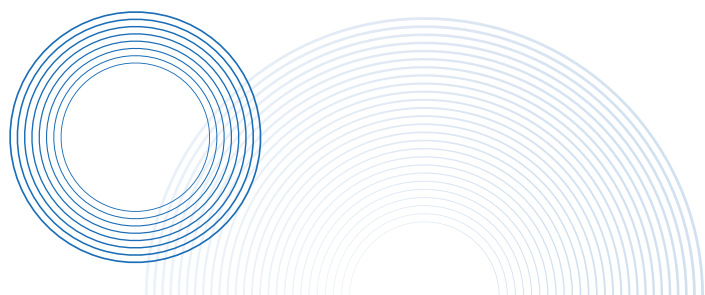
As the person prepares to die, they may go through a process of looking back in search of meaning, saying goodbye to people and places, forgiving and being forgiven, expressing joy and gratitude, facing regrets and accepting death. Some people may not want, or be able to, do these things. It is important to take cues from them and be able to listen, share memories and find ways to say goodbye. Let the healthcare team know if you would like spiritual or emotional support, or if you have important cultural practices at this time.

Caring for yourself

Caring for someone who is dying can be a tiring and stressful time. The experience may bring up unresolved feelings or upsetting emotions. It may help you to talk through your thoughts and how you can look after yourself. Please ask the healthcare team for advice.

Changes you may notice

The dying process is unique to each person. Whilst it is almost impossible to predict the exact time or how a person will die, there are several signs and changes that often occur.



Confusion and restlessness

Shortly before death some people become confused and restless. This is known as terminal restlessness, and it affects people who are dying. There may be a variety of causes and sometimes medications are needed. A calm, quiet and peaceful environment, with reassurance from those close to the person, can often help to relieve this symptom.

Communication

Your family member or friend may find it hard to sustain a conversation. While it may be easier for them to talk after they have rested, just being there will help comfort and support them. You may also wish to hold or gently massage their hands or feet or play their favourite music softly. If they become unconscious, they may not be able to respond to you; however, they may still be aware of your presence and the voices around them.

Becoming unconscious

When or if this happens, repositioning can help prevent soreness and stiffness from lying in the one position for too long. A special mattress may also be used to improve their comfort.

Sometimes an indwelling catheter (tube) is inserted to relieve the feeling of a full bladder; however, it is normal for urine production and bowel movements to slow down or stop.

Sometimes people are unable to cough, and secretions can build up at the back of their throat. This causes a rattling or gurgling noise as they breathe but is unlikely to cause the person discomfort. Repositioning and medications may help.

Breathing and circulation

There may be periods of rapid breathing followed by short periods of no breathing at all. This is known as Cheyne-Stokes respirations and is very common. Again, this type of breathing is normal and is unlikely to cause discomfort. It is also normal for a person's hands, feet and legs to feel cool or cold as their circulation slows down.

Once death has occurred

When people die, they stop breathing and their heart stops beating. They will not respond to any stimulation and their mouth may fall slightly open. Their eyes may be open, but the pupils will be large and fixed on one spot. They may also lose control of their bladder and bowel. When this happens, a doctor or nurse will attend and confirm their death. During this time, you may wish to contact a close friend or relative, spiritual carer or cultural advisor to be with you.

Take your time saying goodbye. The healthcare team will explain what the next steps are and help you access extra support if you need it.

Ward phone number:

Questions:

Please provide this information sheet to the family/carer(s).