

Caring for the dying

Fact sheet

About dying

Caring for someone during the last few weeks and days of life can be a worrying and demanding time for family and friends. Many different feelings and emotions will surface. The day to day matters of life still need to be managed and there are often many other matters to consider and to manage.

Everybody realises that death is an inevitable part of the life cycle. Death, as the ultimate human mystery, is often feared but for most people it is the process of dying that is more fearful.

As a society we have lost our familiarity with death as an everyday part of life.

People fear pain and distress but most fear the loss of control that happens with being ill and dying.

Those caring for the dying have similar fears and often feel helpless and vulnerable in the face of death. For most carers it may be the first time they have been close to a dying person, they may never have seen anyone die before and are unsure of what will happen.

Being prepared for what may happen can make it a little easier to cope with the situation. Nobody can accurately predict the precise time of death, and this leads to levels of uncertainty that can cause distress and difficulty for individuals and families.

About Death

As a society we are immersed in the images of death on television and the cinema. In real life our exposure to someone close to us dying is rare. We may have built up expectations of what will happen which are different from the reality of the dying process before us.

The manner in which someone dies varies depending on the trajectory of the condition leading to death. Where death is anticipated as the result of a terminal illness, there is, most often, a gentle winding down that may take several days as the person starts to 'let go' of life. Sometimes these changes appear a few hours before death, sometimes a few days. The moment of death is usually peaceful without struggle and generally death is preceded by a short period of decreased consciousness or coma.

However, there are some occasions when sudden changes can occur. Some of these changes can be a part of the disease process happening without warning. Other changes can be unrelated to the disease process and catch us unawares.

Your doctor and the palliative care team will help you prepare for the unexpected as well as the expected events particular to your situation.

Changes you may notice and what you can do to help

The changes mentioned here are common to expect in the last few weeks of a person's life. Not all the changes discussed will occur with every person, nor will they occur in any particular sequence.

Appetite and Thirst

The person's appetite will decrease, and they may have little desire to eat or drink. This is a natural process and is not uncomfortable for the person. Providing food and drink is a large part of the nurturing and caring role and it is difficult to let it go and not feel neglectful; however there are other things you can do. The attempt to feed someone who has no desire to eat leads to conflict and distress on both sides.

If a person complains of thirst, it is usually a sign of a dry mouth and throat rather than dehydration. Regular sips of water, sucking chips of ice or pieces of frozen pineapple, or using a moist mouth swab help to correct the feeling of thirst. Attention to detail regarding mouth care can really make a difference to comfort at the end of life.

Sleep and Alertness

As the body changes the need to conserve energy becomes paramount. Recharging "the batteries" through sleep and naps is common. People may spend a lot of time asleep and may be drowsy and difficult to rouse. It is best to talk to the person when they seem most alert, and allow them to sleep when they want to. There is no need to shake the person or to speak loudly.

You can bring enormous benefit to the person you are caring for simply by sitting with them, holding their hand and talking to them. Even if the person does not respond, they can probably hear you. Don't underestimate the value of these simple things. 'Being with' can be more important than 'doing for'.

Temperature and Circulation

The body's temperature may fluctuate. Hands, feet and legs may be increasingly cool to the touch, sometimes they become blotchy and darker in colour as circulation changes.

If the person indicates that they feel cold use light bedding to keep them warm; however too many bedclothes or an electric blanket may make them hot and restless. Provide good ventilation. In warm weather a fan to circulate the air and cool damp towels can help if the person seems hot.

Continence

As the person drinks less, they produce less urine and it will become stronger and darker in colour.

When the person becomes unable to get to the toilet, you may need some equipment such as a urinal, bedpan, or absorbent pads and sheets. A waterproof sheet protects the mattress.

Your community nurse or palliative care nurse can advise you about what is needed and assist with the provision of equipment.

Restlessness

Changes in mental state with confusion and restlessness, sometimes becoming withdrawn or having memory disturbance are common in the terminal phase of illness and this is often referred to as Terminal Delirium.

Let your doctor or nurse know so that medications can be given if necessary.

Coping with a restless person is very tiring and you may need assistance.

Speak quietly and slowly, have familiar people close by, play familiar music, consider gentle massage. Leaving a light on at night can be helpful.

Breathing and secretions

The breathing may become shallow, or sometimes deep and rapid due to an acid imbalance in the body. Sometimes there may be long gaps between breaths. These gaps may get longer as death nears.

The person is not lacking oxygen, and unless oxygen has already been in use before, starting oxygen at this time will not help.

Gurgling noises (the so called Death Rattles) may occur due to small amounts of mucous accumulating in the air ways. Generally the person is too weak to cough them up. These noises can be a concern to carers, but are not distressing to the person.

Snoring and snuffling breathing are common as the muscles of the jaw and throat get weaker causing the tongue to drop back. Sometimes a soft short moaning sound with each breath out accompanies this. Suffocation or death from a blocked airway in these situations is extremely rare.

You can often help the noisy breathing by changing the person's position so that they are on their side with their head slightly raised, well supported by pillows. Medication can also be given to slow down the production of saliva and mucous; however this is not always effective. Suction is seldom effective as the mucous is deep and not accessible. Trying to do deep suction can cause gagging and distress.

Just before death, the person's breathing will slow down, and it may seem like they are gasping. This is quite normal and at this point, the person is not aware of it or in distress.

Dying at Home

The information in the fact sheet Dying at home covers the practical aspects of preparing for a death at home and what to do after the death.

Acknowledgement

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Related fact sheets

Dying at home

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