

Kowhai Programme

Support for families, whānau & carers

What to Expect During the Last days of Life

Understanding the Dying Process

Death and dying happens to everybody but the process is individual and each person will approach death in their own way. There are some common changes that you may notice, but which may not occur for each individual. The information below is only a guide. Please feel free to discuss with health professionals involved anything you read here.

Changes You May Notice

There are common characteristics or changes which indicate that a person is approaching death. These signs may come and go during their illness but will become permanent as death approaches.

- Fatigue
- Reduced need for food and drink
- Changes in circulation
- Restlessness and confusion
- Increased sleepiness and withdrawal from talking with people
- Changes in breathing

Fatigue

One of the first things you may notice is extreme tiredness and fatigue, which may be associated with certain times of the day. They may spend a lot of time sleeping, and may tire easily. Sometimes people can sleep more during the day and become wakeful at night. Talk with a health professional if this occurs as there are ways of helping.

Sometimes there is a surge of energy when the person is more alert, may talk clearly and even eat their favourite food when nothing has been eaten for days. This can be understood in physical, emotional and spiritual ways, and can be an indication that the person is getting ready to die. It may last for a very short time or even some hours. Enjoy this period of time.

Reduced Need for Food and Drink

Initially, as weakness develops, the effort of eating and drinking may simply become too much and help with eating may be appreciated. However there will come a time when food and then drink are no longer wanted. This can be difficult as our instinct to offer food and fluid is powerful and natural. But the person no longer requires

food and fluid to sustain them and this is the time to be guided by them as to what they want or don't want.

While they still have some appetite, offer them very small portions of what they like, usually soft and easily digested food. However when they say they no longer want anything it is usually wise to follow their wishes. Your nurse can offer some swabs that you can use to moisten their mouth with a variety of liquids for comfort.

Changes in Circulation

Over time the patient's skin often becomes cool to touch, clammy and blotchy in appearance. This is quite normal and is due to changes in circulation as the body shuts down. Although they may feel cool to touch they do not appear distressed by this. Use the amount of bed covers they usually would. It may be comforting for you both to massage their hands and feet.

Restlessness and Confusion

This can be challenging but is not unusual as patients decline. It is usually due to physical changes that are happening in their body. Sometimes it may be due to a full bladder or bowel so if you are unsure ask a nurse to assess this for you. There are ways of managing both bladder and bowel to avoid the need or want to get out of bed and the nurse can help with this.

Aim for a calm environment. You may want to limit visitors, play music that soothes them, gentle massage of limbs or back can help. Simply reassuring them you are with them and talking with them can also help. Family sharing memories and stories from their lives can be beneficial for all who are there at this time. Try simple changes of position or check for wrinkles in the bed causing discomfort. If it becomes more difficult medication can be given to ease these symptoms.

Increased Sleepiness and Withdrawal from People

As patients gently decline, eating and drinking less, they are also likely to sleep more and be less inclined to participate in conversation. At times they may be harder to rouse from sleep. They will still, through this, be aware of who is with them and of what is being said. They may not be interested in visitors and it may suit you both to limit visitors just to those most important. This is a good time to share stories and memories together.

Don't be afraid to have children or pets visit and spend time with the patient, even if unconscious. Children are a reminder of living, and while they too will grieve, they take their cue from adults around them. It can help their understanding of what and why death occurs. Pets too can bring a great deal of comfort to both the living and the dying with their presence.

Changes in Breathing

Toward the end of life, as the body becomes less active, the demand for oxygen is reduced. This may be comforting to both patient and carer, especially for those who have had breathing problems, as breathing can become easier than it has been for a long time. About half of patients will develop a 'rattle' to their breathing. This is due to a build-up of mucous the person is no longer moving. This does not appear to be distressing to the person but can be to listen to – much like snoring!

When death is very close (within minutes or hours) the breathing pattern may change. Sometimes the breaths may become rapid and shallow, or slower and deeper. Often there are long pauses between breaths, which become increasingly longer. If the breathing becomes laboured remember this is more distressing to you than for the person dying.

You may try changing their position if that eases the noisy breathing. And keeping their mouth and lips moist is very helpful to avoid, dry cracked lips.

Planning Ahead

It is important to plan ahead to avoid unwanted trips to ED, or emergencies overnight. If you have concerns at any time during the day, call and discuss your concerns with a health professional. It is much easier to manage a change in symptoms during the day. If however there are changes overnight the hospice is available to answer the phone 24/7 and the nurses who are there have access to notes and can advise you, or seek further advice from the on call hospice doctor if necessary.

Saying "Goodbye"

It is important, both for yourself and your loved one, to take an opportunity to say goodbye. By this we mean saying or doing whatever you feel you need to that will allow you to let them go. It may be as simple as recounting special memories, or saying 'I love you', 'Thank you' or 'I'm sorry', or simply holding hands. You will know what it is you need to say or do. This is an important part of the grieving process for both the dying person and their loved ones and can allow for a more peaceful death. Allow yourself time alone with the patient, and other family members may also want this.

If you feel that death is drawing close contact the family and friends who you need to inform. It is often difficult to know when to do this but better too soon than too late. You can let them know of any change and then make their own decision on when to come. If it is important to the patient to have that person with them at the end, they will wait for them to arrive. Equally if they die before the person arrives, then they were comfortable with doing so.

How Will You Know Death has Occurred?

While the person's breathing may have been irregular for some time, the gaps will gradually lengthen until breathing stops altogether. The heart will also stop beating and the skin can become more pale or grey. Their eyes will become fixed, with eyelids likely to be slightly open. This can be a very peaceful yet emotional time. There is no rush to anything at all. Spend as much time with the person as you wish.

A health professional, usually their GP, will need to be notified. If death has occurred overnight this can be done first thing in the morning, as can calling a funeral director.

Some people like to give their loved one a final wash, and change of clothes. It can give solace in the last cares, a ritual that helps with grieving. Others prefer to leave their loved one as they are. Whatever is right for you is the right thing to do.