

Kōwhai Programme

Support for whānau & carers

What to Expect at End of Life

Understanding the Dying Process

Death and dying happens to everybody but how it happens 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 everyone. The information below is only a guide. Please feel free to discuss anything you read here with health professionals involved.

Changes You May Notice

There are common changes which indicate that a person is nearing death. These signs may come and go during their illness but will become more consistent as death approaches.

Some may occur over the last few weeks and days such as:

- Fatigue
- Reduced need for food and drink
- Changes in skin colour and temperature

Others are more likely in the last few days and hours such as:

- Increased sleepiness and talking less with people
- Changes in breathing

Fatigue

One of the first things you may notice is extreme tiredness. They may spend a lot more time sleeping.

Sometimes there is a burst of energy when the person is more alert, may talk clearly and even eat their favourite food when nothing has been eaten for days. It may last for a very short time. Enjoy it together.

Reduced Need for Food and Drink

Initially, as weakness develops, the effort of eating and drinking may simply be too much and help with eating may be welcomed.

While they still have some appetite, offer very small amounts of what they like, usually soft and easily digested food.

As people get closer to death there will come a time when food and drink is no longer wanted. This may be difficult to see but is a natural part of dying. Be guided by them as to what they want or don't want.

Your nurse can offer some swabs that you can use to moisten their mouth for comfort.

Changes in Skin

At the end of life a 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. This can come and go over the last few days of life. Although they may feel cool to touch they are not distressed by this as it is a natural change. 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

Some people can become restless or confused 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 this and the nurse can help.

Aim for a calm environment. You may want to limit visitors, and playing music that soothes them, or 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 comforting 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.

"Can they still hear me?"

As patients gently decline, they are still aware of who is with them and of what is being said. This is a good time to share stories and memories together, if that feels right for your whānau.

Don't be afraid to have children or pets visit and spend time with the patient, even if unconscious. Children will grieve, but they take their cue from adults around them and it can help their understanding of what is happening 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, changes in breathing are normal and common. Some patients will develop a 'rattle' to their breathing. This is due to a build-up of saliva the person is no longer moving. This is not distressing to the person but can be to listen to – much like snoring!

When death is very close (within hours or even minutes) 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.

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 are worried at any time during the day, call and discuss your worries 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.

Saying "Goodbye"

It is important, both for yourself and your loved one, to take an opportunity to say goodbye. Saying or doing whatever feels right for you and your whānau.

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 wish to say or do.

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 whānau you want to know. It is often difficult to know when to do this but better too soon than too late.

People will choose to die in the way that is right for them. This may mean waiting for people to arrive and sometimes it may mean waiting until they are on their own. Whatever they choose is the right way for them.

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. This can be a very peaceful yet emotional time. There is no rush to do anything at all. Spend as much time with the person as you wish. Take the time you need until you are ready to contact others.

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 be peaceful giving these 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.



You might like to listen to this topic on the Ending Life Well Podcast available on most podcast sites and on the Otago Community Hospice webpage.

