Te Whatu Ora
Health New Zealand

# When someone you care about is dying in aged residental care: what to expect.



**Nearing the end of life**
The care team will have explained to you that there has been a change in the condition of the person you care about and that they think the person is now in their last days or hours of life. We understand that this is an emotional and challenging time for you.

We hope this booklet will help make this time a little easier by talking about common changes in the last days of life and ways to support the person you care about and yourself. Every person is unique, so every death is different. Some information may only apply to some situations.

**A plan of care**
The care team will do everything possible to maintain the person's comfort and dignity and to support physical, emotional, spiritual, and family well-being using Te Ara Whakapiri guidelines. They will be reviewing the person regularly and offering assistance.

The plan of care for the person you are about will be regularly reviewed. If their condition improves, then the plan of care will be changed. A specialist palliative care team can advise if the person has a symptom or problem that needs additional support.

**Talking with the care team**
The care team will ensure you have opportunities to understand and be involved in the care plan. They will work with you to know how you may want to support the person you care about. Feel free to share as much physical care as you want or help care by spending time together.

The dying person may already have told you and the care team what they want for themselves and what is important to them. You will be able to talk with the care team about this.

Please speak to the care team if anything worries you or if you would like something done differently. Ask as many questions as you need to. Staff are available to provide explanations and support.

## 1. Changes you might see in the person who is dying

This section explains some common changes you might see when a person is close to death. When a person enters the final stages of life, changes may affect their body, mind, or both. These changes are a normal part of the dying process. Changes appear a few days before death, sometimes a few hours. These are part of the normal, natural process of the person's body slowing down. This can be an uncertain time and difficult to predict.

If any changes worry you, please speak with a healthcare team member.
Changes that may happen include:

- Not wanting to eat or drink
- Becoming restless
- Getting cold hands and feet
- Sleeping more
- Becoming confused
- Changes in breathing
- Having pain or discomfort.



These changes do not happen in a set order. Not all of them happen to everyone.

**Not wanting to eat or drink**

When close to dying, many people stop wanting to eat or drink. This is normal, but it can be upsetting for those who care about them. The person you care about will be supported to eat and drink for as long as possible. Small tastes of their favourite food and drink may be appreciated even if they have lost their appetite for more than a taste or sip. Sometimes, even small mouthfuls may be inappropriate if the person cannot swallow. You can still help the person by gently wetting their mouth and lips using a swab. Applying a lip balm can also help. This will usually be enough to keep the person comfortable. The care team can help, too.

**Sleeping more**

As a person is dying, they may spend more time sleeping. When they are awake, they may be tired and sleepy with little energy. They may not want to speak and may find it hard to concentrate. They may slip in and out of consciousness. This is normal. It is important to remember that even when the person seems less conscious, they may still be able to hear you. Let the person relax and rest. Make the most of the times when the person seems more alert.

**Getting cold hands and feet**
The person's hands and feet may feel cold and may change colour. This is because their heart is only sending blood to the body's vital parts. You can put extra blankets over the person's hands and feet to keep them warm and comfortable.

**Becoming restless**
Sometimes, the person who is dying can become restless. They may appear anxious or make repeated movements, such as pulling at the blankets or their clothes. This is usually because of physical changes in their body and is part of the dying process.

Talk to the healthcare team if the person's restless actions upset them or you. The care team will check if there are any physical causes of discomfort that they can help with. You can help by sitting with the person and reassuring them. Even if they don't seem responsive, the person may be able to hear you and find your voice comforting. You might be able to think of soothing music or smells, such as a favourite perfume or flowers. Some medications can help if people are anxious or can't settle.

**Becoming confused**
The person may be confused about where they are and who you are. They may see or hear things that are not there. They may also appear to speak with people who have already died.

You can acknowledge their distress and gently reassure them that they are safe. Let them know who you are and that you are there to help. You might be able to keep familiar objects in their line of sight or talk about familiar comforting things. Medication can be given to help the person if they are distressed. Talk to the healthcare team if the person's confusion upsets them or you.

**Having pain or discomfort**
You may worry that the person you care about is in pain or is uncomfortable. Not everyone experiences pain when they are dying, but unfortunately, some may. The care team will do all they can to ensure the person is comfortable. The care team will give medication as needed to ease the symptoms and relieve pain. Sometimes, distraction, changing position, or gentle massage may help. The care team will be able to discuss ways you can help and answer any questions or worries.



## Changes in breathing

As a person nears death, their breathing may change. It may get fast or become slow and shallow. When they are near death, there may be long gaps in a person's breathing. This is not distressing for the person but is part of the dying process. You can continue to hold their hand and reassuringly speak to them. This change in breathing can be a sign that it's time to contact family/whānau members who might wish to be present at the time of death.

You may notice gurgling noises from the person's chest or throat, which can be upsetting for you to hear. This type of breathing happens because the person can no longer cough or clear their throat. Air moving across the pooled secretions vibrates noisily, like sucking the last of a drink with a straw. This noisy breathing does not usually disturb the person. You can think of it as being like snoring. The noise does not mean the person is in pain, uncomfortable, or drowning. Playing background music may help take your mind off the noise. Sometimes, raising the bed or helping the person to turn to their side can help. Medication can help dry up secretions, and the care team may advise you on ways to help with mouth care. Talk to the healthcare team if they seem distressed.



## What to do if someone dies while you are with them

It may be that the person you care about dies while you are with them. When you know the person has died, you do not have to do anything quickly. It is a very personal moment, and you can take your time.

When you are ready, tell the healthcare team. They will arrange for a medical professional to confirm the death. You will usually be able to stay with the person who has died until you feel comfortable for the person to be moved. You can take time to shed a tear, talk, sing, pray, or sit if you wish. The care team can support you at this time and will explain the next steps.

## When someone dies when you are not with them

You may not be there at the moment of death. You may not have been able to spend as much time as you would have wanted to with the person before their death. This may make it more difficult to feel that the death is real. It might also bring up feelings of regret, anger or even guilt. Try not to dwell on these painful aspects. A relationship is made up of all of life’s shared times; this can never be taken away from you.

## After death

Some families may wish to help the care team to wash and dress the body in the chosen clothes or to arrange their hair. The care team can arrange the necessary paperwork, such as the death certificate. The care staff can liaise with you and the people helping you with arrangements (such as a funeral director) about moving the person who has died when you are ready.

## 2. Supporting the person and yourself

The time approaching death can be an emotional time for everyone. The person dying and the people caring about them may go through a range of emotions. These may include shock, anger, upset, fear, denial, helplessness, relief, frustration and acceptance. These feelings can come and go in any order. You and the person may go through all of them, some or none of them. People respond in different ways. There is no right or wrong way to deal with these feelings.

**Talking about death and dying**

Not everyone can hold a conversation in the last days of life, but sometimes sitting with the person and listening is important. Careful listening helps the person who is dying to share their feelings. It may also help you to understand their concerns. Be respectful of what the person says. Try to avoid brushing them off or changing the topic. Most people want to be listened to as they express their hopes and fears. They may also want to know that they are not alone.

Everyone is different. Some people want to focus on something other than what lies ahead or talk directly about the end of life. However, they may want to be reassured about what is happening and that they are getting care and support.

Some people think about the meaning and purpose of life. Let the dying person talk about what is on their mind is helpful. Let them take the lead in the conversation. If you can, it is good to respond to any questions honestly. These are deep and personal questions. Many people get consolation just from saying them out loud. If you feel stuck for words, you could say something like: “Are you worrying about something?” or “That’s a big question, have you been thinking about that for a while?”. Some people find it helps to talk things through with a spiritual leader. You may find the experience of being with a dying person is meaningful and spiritual for you, too. Your dying relative or friend may want to pray, meditate, or reflect with you.

It is important that you look after yourself during these conversations. There is more about looking after yourself later in this booklet.



## Talking to children about dying and death

Children who are close to the person who is dying may have many questions. Reactions to grief will vary according to the child and their age. Even very young children can tell when something is wrong, so try to be as open and honest as possible. Use clear language they can understand, such as 'dead' or 'died'. Terms such as 'gone' or 'gone to sleep' can confuse and frighten children. Information about supporting children through grief is available from the
The Grief Centre https://www.griefcentre.org.nz/resources/
Kids Health https://www.kidshealth.org.nz/bereavement-reactions-children-young-people-age-group
and Skylight provides information and counselling www.skylight.org.nz

## Touch

You do not always have to use words to communicate. Indeed, you may find it hard to find words for what you want to say to the dying person. Touch is a good way to let the person know you are there. This simple act can be valuable. It may also be comforting for both of you.

You could hold the person's hand or lovingly massage in hand cream. Many people find this reassuring. It can also help the person to relax, sleep or deal with discomfort. Sensing you are there can bring comfort and peace. When a person isn't able to get out of bed, massaging their heels and elbows can also help relieve the pressure of lying down all the time.

## Being quiet together

As the person becomes weaker, they will have less energy for talking. Sometimes, they may not want to speak or be unable to talk. That is OK. Just knowing you are there and ready to listen can be reassuring. It can be good to be together in silence.

## Letting go



Saying a final goodbye is never easy. Tears and talking about memories can be part of saying goodbye and can help you both to let go. Some people want to be there every moment, others find it difficult. Some people do not get to or even want to, say goodbye. Some people do not cry. It is important to remember that there is no right or wrong way to respond. You must do what feels right for you. It is important to remember that everyone is different, and their relationship with the person who is dying is unique.

## Looking after yourself



It can be hard to think about taking care of yourself in the midst of caring for someone who is dying. Try to find little ways to look after yourself so that you have the strength to spend time with the dying person and others. The following tips might be helpful to you:

- Remember to eat and to keep hydrated. Your body has needs, and you need to look after yourself.
- It is OK to feel overwhelmed or to have feelings of loss even before the person has died. If you can, reach out to people for support and share your feelings.
- Keep talking with the people who are closest to you, like your family and friends. Even if those closest to you are not physically near, contact them and, if possible, talk with someone each day. Having conversations keeps communication flowing and can remind you that people are thinking about you.
- If you get offers of help, allow yourself to accept them where you can.
- Keeping some routine, like mealtimes, can be helpful. You can try getting outside, too, if possible.
- Seek information and support from the healthcare team. They are there to answer any questions and support you.

**Grieving**

Grief is a natural process. It is what happens as people adjust to loss and change. Some people grieve before the person dies, as well as afterwards.

Even if death is expected, many people feel shock and disbelief when it happens. You may appear to be coping but can also feel you are going through the motions. Feelings and thoughts can come and go in waves. Grief does not happen in a set way, and it takes time. The healthcare team and your GP can help you by providing some information and advice.

## 3. Useful resources and information



Here are some useful websites that provide online resources about grief:

- The Grief Centre www.griefcentre.org.nz
- Skylight (supporting young people and their families): www.skylight.org.nz
- Mental Health Foundation https://mentalhealth.org.nz/conditions/condition/grief-and-loss

If you would rather talk to someone by phone about your grief:

- Lifeline free counselling service 24 hrs/day, 365/days a year 0800lifeline — 0800 543 354
- Skylight – 0800 299 100 ; 9am–5pm weekdays.

Your GP can recommend local support and counselling options to help you work through your loss. Reaching out to your marae or kaumatua may also be a helpful way of finding support.

These sites provide practical information about what needs to be done after someone dies:

- Citizens Advice Bureau https://www.cab.org.nz/article/KB00000594
- New Zealand Government https://www.govt.nz/browse/family-and-whanau/death-and-bereavement/what-you-need-to-do-when-someone-dies/

The Te Ipu Aronui website shares stories to help support Māori whānau (families) to provide care to people at end of life:

- https://www.teipuaronui.co.nz/

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