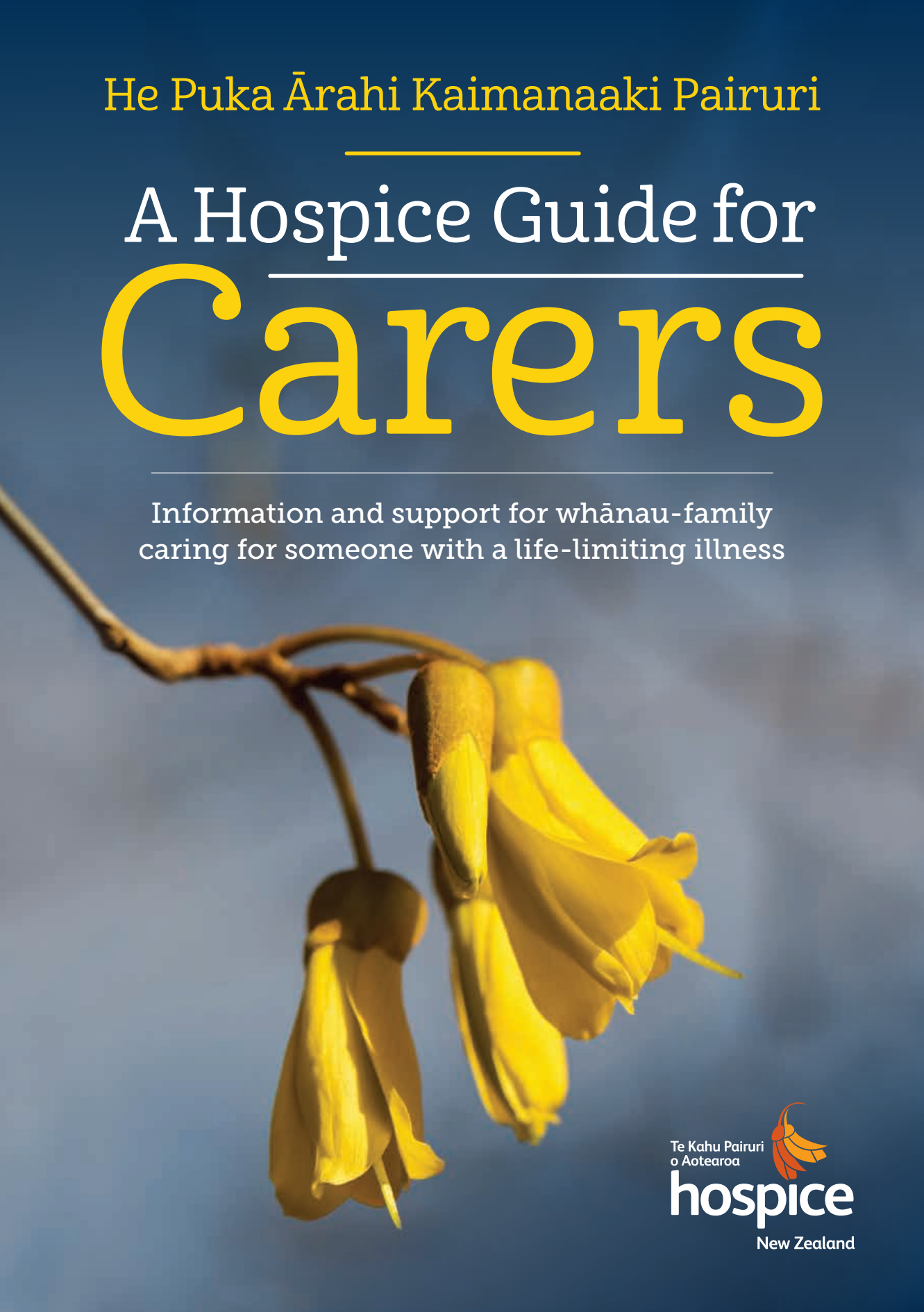
He Puka Ārahi Kaimanaaki Pairuri

A Hospice Guide for Carers

Information and support for whānau-family caring for someone with a life-limiting illness



Te Kahu Pairuri o Aotearoa
hospice New Zealand

Acknowledgements

Te Kahu Pairuri o Aotearoa – Hospice New Zealand acknowledges and sincerely thanks everyone who reviewed drafts and provided insightful critiques for this 2024 edition, and to those who have so willingly contributed their expertise or personal experiences to this guide.

Ka hikoi tahi tātou me ngā whānau

We walk together as one with the whānau

Local provider contact details

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Tēnā Koutou Katoa - Welcome

There are few experiences more challenging than caring for someone at the end of their life.

You are not alone

Across our country, many New Zealanders are caring for someone who has a life-limiting illness.

> "One night I took a walk outside. I looked up into the night sky. I wondered how many other people are out there, just like me, trying to support someone they love who is dying. It helped to remember I'm not the only one." Annie

There are also compassionate palliative care teams working in communities, hospices, hospitals, nursing homes, and other residential facilities to support terminally ill people and their carers.

About this Carer's Guide

This guide is for whānau-family carers. Whenever the term whānau-family is used, it is intended to also include close friends.

It provides practical information to support you through this time and shares tips and insights from carers who have 'been there'.

We encourage you to see our Hospice New Zealand website for more helpful resources.

You may also like to listen to the Ending Life Well podcast series, produced by Otago Community Hospice and supported by Hospice New Zealand. It is available on all good podcast platforms.

If you have questions not answered in this Guide, talk with the healthcare team supporting you and the person you're caring for.

If you find reading English difficult, perhaps ask someone to read the Guide to you or to translate it into a language you know.

Contents

6 Understanding Palliative Care and Hospice Care

6 What is palliative care?
7 What is hospice care?
8 The palliative care team

11 Being a Carer

12 Hearing their diagnosis
13 Caring involves a variety of activities
14 The rewards of caring are many
14 Caring can also be challenging
15 Understanding anticipatory grief

18 Caring for Yourself

18 Your own health and wellbeing matters
19 10 self-care tips for carers
22 Te Whare Tapa Whā
24 Tools for coping with stress
29 Using the help and support of others
33 Some helpful links for carers

35 Caring for the Unwell Person

35 What they may be going through
36 Identifying their needs
37 Supporting their day-to-day care
37 Communicating well with the healthcare team
39 Receiving updates on the person's health
39 Staying hopeful
40 Supporting their spiritual needs
40 If you are concerned about their mental health
41 Managing visitors
41 Caring for your relationship

44 Talking about Dying

47 A Māori Approach to Caring for a Person at the End of Life

47 A Māori approach to caring for a person at the end of life
50 Rongoā Healing – Māori Treatments at the End of Life

52 Supporting Children and Young People

55 Managing Care at Home – Practical Tips

55 Organising the house – a helpful checklist
59 Providing personal care
65 If the person has a disability or special care needs
65 Using special equipment
66 Giving medications
68 Natural therapies
69 Providing food and drink
71 Understanding and dealing with common palliative symptoms
75 When to call for extra help

77 Planning Ahead

78 Advance Care Planning (ACP)
79 Possible organ or tissue donation
79 A Do Not Resuscitate Order (DNR)
80 Organising personal documents
81 Financial Matters
81 Enduring Powers of Attorney (EPA)
83 Writing or updating a Will
84 Executors of the person's estate
84 Guardianship for any tamariki–children or rangitahi–young people
85 Decisions about what will happen to the person's body
86 Planning a Farewell

Contents | Continued...

88 Caring for the Person in a Hospice, Hospital, Nursing Home, or Residential Facility

91 Caring in the Final Days and Hours of Life

91 Signs and symptoms when death is close
94 How to tell when the person has died
94 What to do if the person dies at home

97 After the Person Has Died

97 Some important tasks
98 Grieving your loss
100 What can help during grief?
101 If grief gets hard to manage
101 Gradually moving forward

103 Glossary

103 A helpful list of words and phrases used in palliative services
106 Personal notes



Te Manaaki Pairuri me ngā Rōpū Ratonga Pairuri

Understanding Palliative Care and Hospice Care

What is Palliative Care?

Often people can live with a terminal illness for many months or years, but they may want or need some extra support as they near the end of their life.

Palliative care provides such support, with compassion. It aims to maintain the person's quality of life, or even improve it, as much as possible. It focuses on providing comfort, managing symptoms, relieving pain, and assisting the person to die with dignity. The person's physical, mental, emotional, cultural, spiritual, and social needs are all supported.

Palliative care also includes supporting the members of a person's whānau–family, both during their illness and after they have died.

Supporting each carer's wellbeing is considered a priority.
All carer contributions are highly valued.

A palliative care team can deliver care to a person wherever they are – in a home, hospital, nursing home, residential facility, or hospice inpatient unit. Initially, care is provided by local district nurses, a local doctor (GP), and other health professionals in the community. This helps a seriously ill person to cope well at home for as long as possible. When more specialist care is needed, palliative care professionals work alongside local health providers to provide it. At some stage, this might involve a stay away from home, such as in hospital or in a hospice inpatient unit. Everyone's situation is different.

Palliative Care is respectful, inclusive, professional, and compassionate.

For as long as it is needed, palliative care provides dedicated support for the unwell person and their carer/s and whānau–family.

He aha te mea nui o te ao -
he tangata, he tangata, he tangata

What is most important in this world -
it is people, it is people, it is people

What is Hospice Care?

Hospices are community-based service organisations specialising in providing free palliative care for whoever needs it, wherever it is needed, for as long as it's needed.

There are 33 hospices around Aotearoa New Zealand. Each one helps people with an advancing, life-limiting health condition to live as fully and comfortably as possible.

Accepting hospice care doesn't ever mean 'giving up'. It means accepting professional help and support to make the most of every day. Hospice staff often hear people say they wished they'd accepted hospice care sooner.

A hospice provides care for the whole person. This means they don't only care for their physical and medical needs, but also for their mental, emotional, social, cultural, and spiritual needs. Every person is seen as unique, with their own values, concerns, and wishes.

You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.

Dame Cicely Saunders
Founder of the modern hospice movement

A Hospice team also supports the ill person's carer/s, and their whānau–family.

Hospice care usually begins when a person's illness needs specialist palliative assistance. They may be referred by a local doctor (GP) or a relative, or they can self-refer.

Hospice care isn't only provided by medical staff.

Hospice teams include people with many speciality skills to support both the unwell person and their carer/s, and whānau–family. ▶ **See page** 9.

All care and support provided by a hospice is completely free of charge.

Most hospice services can be delivered to wherever a terminally ill person is living. A hospice team will work closely with the person's local doctor (GP) and any other healthcare providers involved in their care, such as district nurses and pharmacists. They will usually see an unwell person in their home or as an outpatient. However, sometimes the person may need to spend a few days in their local Hospice Day Unit or Inpatient Unit, or possibly in a local hospital.

> "Hospice cares for people in any place you call home. We are in the community, in people's homes, in the park, or in our purpose-built facilities. Wherever we need to be, we are."
>
> Lea – Clinical Services Manager, Nelson Tasman Hospice

The Palliative Care Team

A palliative care team is a multidisciplinary team (MDT). This means they are a healthcare team made up of differently skilled professionals working together to provide a compassionate, specialist service tailored to what each person needs. The team can support you to care for your unwell person at home or wherever they are staying. It helps to get to know who's who in your local team. Perhaps keep a list of their names and roles handy. ▶ **See tips** for communicating with them well on page 37.

It's okay to open up, to feel whatever you feel, to talk, and to enjoy life. We're sharing the emotional journeys of everyone in our care, including whānau–family.

Te Kahu Pairuri o Aotearoa – Hospice New Zealand

Each team member contributes different knowledge and skills.

A team will often include a mix of these kinds of roles:

---

local doctors (GP) | specialist doctors

hospice/hospital/nursing home/residential facility healthcare staff

hospice community or district nurses | social workers

physiotherapists | dieticians | pharmacists | natural therapists

occupational therapists | needs assessors | counsellors

whānau–family support workers | chaplains | spiritual carers

rongoā Māori practitioners | traditional cultural practitioners

cultural liaison | art therapists | music therapists

home care or personal care assistants

e.g. those assisting with personal hygiene care, cleaning, meals, or gardening

centre receptionists | administrators | hospitality providers

day programme coordinators | drivers | educators

support group facilitators | trained volunteers

bereavement support carers

An unwell person's carers, whānau–family, and community are also a highly valued and important part of the support team.





Te Noho hei Kaimanaaki
Being a Carer

Every situation is different, but often whānau–family want to help care for and support a person whose life is nearing its end.

Many people don't think of themselves as a 'carer' at all.
They're just doing what they feel they need to do.

Most people see themselves *first* as their unwell person's spouse or partner, parent, child, grandchild, sibling, whānau, or friend. However, if you are now providing more regular help and support for them than before their health situation changed, you are also a carer.

All carer's circumstances are different.

- People provide care for different reasons. You might want to, it may feel natural or right to, or you might feel obliged or expected to.
- You may have been providing care and assistance for some time or perhaps you have started more recently.
- You might be considered the person's main carer or be one of several carers who take turns to help.
- You may be providing fulltime care, perhaps even living with the person, or providing care as and when you are able to. You might be doing your best to provide care from a distance. Carers are all in different situations.

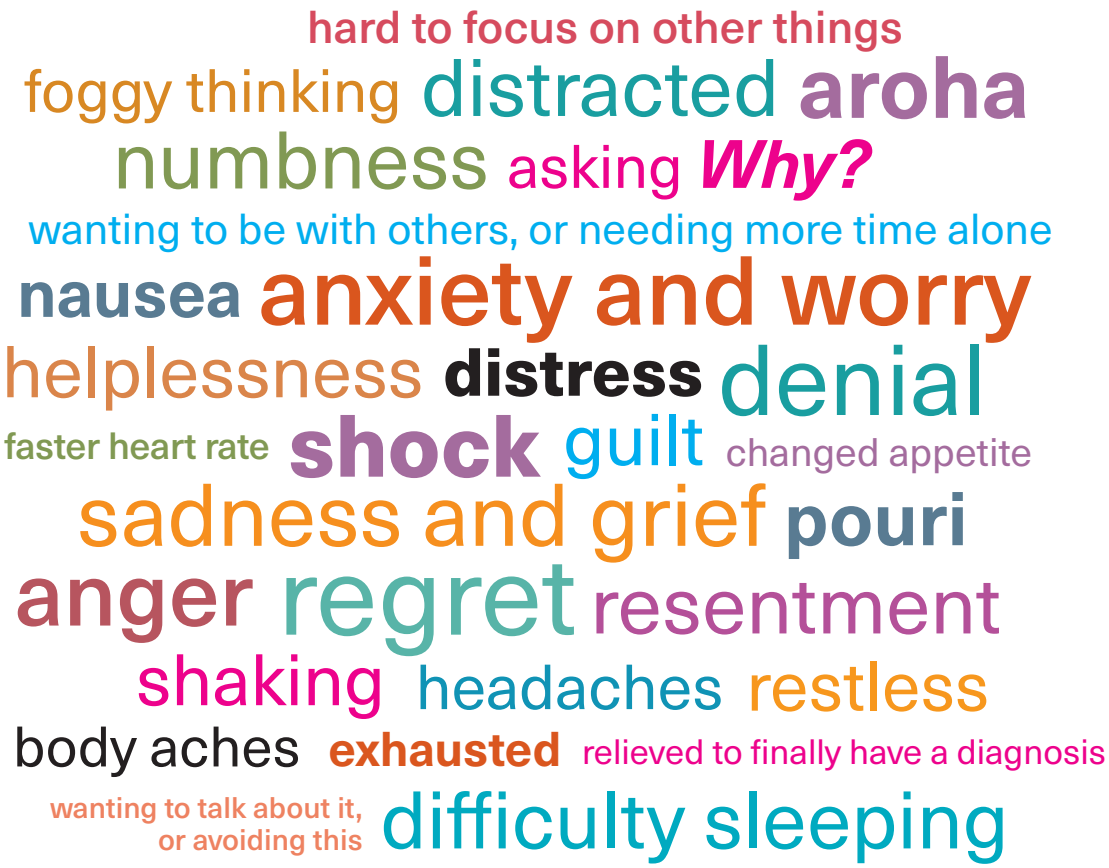
> "It was a relief when I let myself share the load a bit. Having someone visit, make a meal, do washing, clean, or stay for a while meant I could catch up on things or grab some time for myself." Mel

Hearing their diagnosis

Finding out that someone's life now has a time limit can be very difficult. It may come as a shock or be somewhat expected. The estimated time given until death may be long, or it may be short.

You may have experienced a wide range of reactions. These might have come in waves, all at once, or just gradually started as your initial shock wore off. Your reactions are a normal part of adjusting to this challenging new situation.

Common reactions to hearing someone's illness is terminal include:



Give yourself time for the diagnosis to sink in.

During this time, caring for yourself well helps give you the strength and energy to cope, and to support the ill person as best you can. ▶ **See page** 18-33 for self-care tips.

"I live thousands of miles away, but message or video call most days. I can't do the everyday tasks, but I'm giving ongoing emotional support." Claire

Caring involves a variety of activities

Carers usually have a range of tasks, such as...

Providing practical support for daily activities, such as eating, drinking, bathing, moving around the house, and possibly toileting. (Often a trained helper can assist with showering and dressing.)

Checking symptoms.	**Helping manage** medication.	**Going with them** to appointments.
Communicating with the healthcare team. Advocating for needs to be met.	**Helping with** physical or occupational therapy exercises.	**Talking with** the unwell person. Keeping each other company. Sharing some enjoyable activities.
Giving emotional support e.g. listening, reassuring, encouraging, celebrating achievements, being with them in hard moments.	**Supporting the unwell person** with any planning or decision making that's needed and, if asked, assisting them with business, legal, or financial matters.	**Co-ordinating with** other whānau – family and close friends to provide updates, or get support.
Looking after household chores, like shopping, washing, or cleaning.	**Visiting** in a hospital, hospice, or residential facility. Possibly helping with a few basic tasks.	**Providing or organising** transport.

The rewards of caring are many

Many carers say it's an experience they are grateful for, although it's a challenge.

They value:

- Just being with the person
- Helping them to make the most of their time
- Making special memories together
- Providing comfort and encouragement
- Giving back to someone who has cared for them
- Deepening their relationship, perhaps putting right any past hurts
- Getting closer as a whole whānau–family
- Knowing they're doing what they can
- Learning how to talk about hard things and finding some new coping skills
- Learning more about life and death.

> "When he smiled back at me, I took a mental photo of the moment. I'm so grateful for this time together." Josie

> "I could tell that just sitting there with her made her calmer and more settled." Ron

Caring can also be challenging

Most carers say they have good days and hard days.

Many people feel unprepared or unsure about how to provide care, until they learn more. Understanding the health system and new medical language can be difficult until it becomes more familiar. Losing your normal routines and adjusting to ongoing changes can be very unsettling. Trying to balance caring responsibilities with other obligations can also be demanding, such as work commitments, parenting, or ongoing community commitments.

Often carers comment that emotions can get intense and be hard to manage at times. There may be moments of feeling really overwhelmed.

> "It can get really hard, but I still wouldn't be anywhere else." Tjay

Some tasks can be physically demanding. Carers can become very tired. Their own wellbeing can get overlooked. Sleeping can become more difficult when they must stay alert to the ill person's 24/7 needs.

Sometimes carers might initially feel awkward or uncomfortable talking about dying and end-of-life matters. They may never have had conversations about these things before.

> "I didn't want to talk about it, but he did.
> Once we got going, it was actually okay." Kara

Despite all the hard work they do, carers can sometimes begin to feel they're invisible to others and taken for granted. With lots of comings and goings, more people around, and the ongoing stress and uncertainty, it's not surprising that tensions can sometimes increase. Carers also often find that covering extra expenses and organising support services isn't always straightforward.

When carers look after themselves well, challenges of all sizes can become more manageable.

See pages 19-21 for self-care tips from other carers.

Understanding anticipatory grief

Many carers find their grief doesn't wait for the person's death to happen.
This is called *anticipatory grief.*

Right from the moment of diagnosis, it's understandable to experience some grief reactions. Not only is the person dying, but other losses appear along the way. For example, changes in their personality or appearance, or their loss of independence or mobility. You may find you're grieving for how things used to be, for your relationship before, for activities you can't enjoy together anymore, or for the things once planned and hoped for.

> "It was confusing to feel this way because he was still alive.
> I figured out it was just part of the territory." Jen

Grief is a natural process that helps us gradually adjust to difficult change and loss. Everyone's different. However you react, it will be normal for you.

Your grief will be like your fingerprint – unique



Common anticipatory grief reactions include:

Strong up and down emotions of all kinds, or feeling numb	Thinking or talking about the expected loss, or avoiding it	Hoping the person will live longer, against the odds
Body reactions, e.g. muscle aches, nausea, upset stomach, shallow breathing, shakiness	Crying more, or unable to cry	Difficulty concentrating, distracted, forgetful, brain fog
More irritable, frustrated, emotional outbursts	Sad to be losing the person a little more each day	Instinctively drawing on spiritual, cultural, or faith beliefs or practices to find meaning

> "I couldn't stop crying but my partner couldn't cry one tear. We had to accept we were reacting in different ways." Kimberly

> "It felt weird already thinking about her being dead, but it felt good knowing she'd be welcomed by Atua and our tīpuna and would always stay in our lives. My beliefs helped a lot." Ahi

If you have a history of anxiety, depression, or other mental illness

This challenging situation may make you more vulnerable to increased mental distress. Reach out to people you trust, your local doctor (GP), your local mental health service, or to a counsellor or psychologist for ongoing help and support to keep well.



Te Manaaki i a Koe anō
Caring for Yourself

Your own health and wellbeing matters

Looking after yourself well helps you to cope with whatever each day brings, and to provide the care you want to give. A carer and the person cared for both benefit when the carer makes regular self-care a priority.

Carers work hard. Being tired can become what's 'normal'. You might not always realise how weary you are, because you just keep going. This is why carers need to make regular times to rest.

Whānau–family carers are not machines. We have human limits and human reactions. We can't simply keep going and going and going without consequences, however much we wish we could.

Carers NZ

Use some stress-relieving strategies

Ongoing stress can have a greater impact on us than we think. Stressed people are more likely to have accidents, get sick, forget things, get irritable or angry, or not sleep well. Stress can make it harder to think straight, remember information, or make good choices. It can affect our physical and mental health and lower our overall wellbeing.

However, if we make regular time to de-stress and relax, even in a few minutes grabbed during the day, it can lift our mood, give us a more positive attitude, boost our sense of humour, increase our motivation, and help to keep us well. Even small acts of self-care can have a big effect.

We might also need to think about doing some things differently, like eating more healthy food, drinking more water, accepting others' support, seeing a doctor, getting some exercise, or organising some respite care.

10 Self-Care Tips for Carers



Every day, get the basics right

These keep you functioning well, so don't be tempted to ignore them. Eat healthy food regularly. Drink enough water. Do some exercise – even just simple stretches or a quick walk to your letterbox or down a corridor and back. Get good sleep, as best you can. Grab snatches of rest when possible. Connect with others – don't isolate yourself. See a doctor if you're unwell or struggling. Try to avoid or reduce using alcohol or drugs, which can negatively affect your health. Breathe in some fresh air. Even just sitting in the sun for a few moments gives you some vitamin D and feels good.

Treat yourself like you'd treat a close friend going through difficult times – with kindness, compassion, and care.



Keep a positive outlook

Keeping positive is a key resilience skill. The more positively we think, the more positively we feel and act. Look for even small positives in your situation. Notice the good moments. Each evening, try thinking of 3 things that went well or that you're grateful for. Perhaps note them down.



Keep connected with others

Try to talk to someone outside of your carer life each day. This helps keep your life in balance. It might be hard to get to social events but try to keep up key relationships to avoid becoming isolated. Others can help give you emotional encouragement, practical support, or some relaxed time out. Social connections are essential for good mental health. Perhaps look out for hospice or community support groups for carers.



Do something each day to lift your spirit

At times your life may feel like it's just revolving around illness, dying, and the health system. Doing things you enjoy helps keep you linked in with the rest of your world. What makes you feel good? What improves your mood or makes you smile? Make some time for these things to happen regularly, as best you can.

Perhaps you could message or call a friend, look out a window at the view, have a hot drink, listen to favourite music, or watch a movie you enjoy. Maybe take a refreshing shower, have a warm bath, sit somewhere calm, get out into nature, read a book, look at photos, spend time on a hobby, watch sport, or play with your pet. What works for you?



When trusted people offer help, say yes

You might not be used to others offering you help, but if it supports you, **say yes**. Let trusted others help with practical things like household chores, meal preparation, transport, childcare, or shopping. **Say yes**, even if it's not always done exactly how you'd do it. Just keeping you company might also be supportive. Find out what support services your local hospice offers to carers. If you're working, let your manager or boss know what you're coping with, so they can support your situation too.



Find ways to express thoughts and feelings

An up and down rollercoaster of strong thoughts and intense feelings can be hard to manage. Emotions can build up, like a volcano, and threaten to erupt. Finding ways to express what's inside can bring some relief. Here are a few ideas to consider:

- Talk to someone you trust
- Write thoughts and feelings down
- Cry if you need to
- Shout into a pillow, or into the wind
- Walk, run, dance, exercise, dig in the garden, kick a ball
- Use music, waiata, sing your heart out, play an instrument.
- Visit a gym and punch the feeling away
- Use karakia or prayer
- Make or create something
- Breathe it out **See page** 24



Make room for laughter and fun

Many carers say it's their sense of humour that helps them most. Having a sense of humour and laughing helps us to lower stress, release body tension, strengthen our immune systems, and lower blood pressure. Look for the humorous side of things when you can. Share a joke. Enjoy funny memories. Call or visit with people who make you laugh. Watch or read something funny. Laughter really is good medicine.



Try some new coping tools

Keep doing what's worked for you before but be open to trying some new ways to cope with stress too. Perhaps learn how to breathe slowly and deeply, or to stretch in ways that relax your body's tensions. Maybe try some meditation or mindfulness, or some new kinds of exercise and movement. You might find writing in a personal diary or journal helps you let thoughts out, instead of keeping them in. **See pages** 24-28 for some stress-busting tools.



Don't expect too much of yourself

We all have limits. Aim to do your best but remember no one is perfect. Watch out for negative self-talk. Speak kindly to yourself and show yourself some understanding. Look for ways to simplify things, so daily life can be made a bit more manageable. Notice what you've been doing well. Let go of unrealistic expectations and demands. Learn to say no when you need to. Don't take on more than you can handle.



It's okay to reach out for extra help

Carers often say they have times when they feel overwhelmed or unable to cope. Let the healthcare team or your local doctor (GP) know. Reaching out for help isn't a sign of weakness. It's a strong and wise choice. Ask if some respite care can be arranged or seek some extra help for yourself or your whānau–family, if needed. **In times of acute stress or crisis call or text the helpline 1737** to speak to a counsellor for some immediate support. This is a free service and it is available 24/7.

Te Whare Tapa Whā

Te Whare Tapa Whā is a helpful way to think about our hauora–health and wellbeing. It's a Māori concept, based on the pillars of a wharenui–meeting house. When one part of the wharenui isn't standing up properly, the whole wharenui becomes unbalanced. We need to give attention to each of the important parts of ourselves to gain hauora–health and wellbeing. This keeps us strong and well balanced. Connecting with our whenua–land also helps to make sure our whole wharenui's foundations are kept strong.

All these important parts of us are needed for hauora–health and wellbeing:



Te taha tinana

Our physical health



Te taha hinengaro

Our mental and emotional health



Te taha whānau

Our social and family health



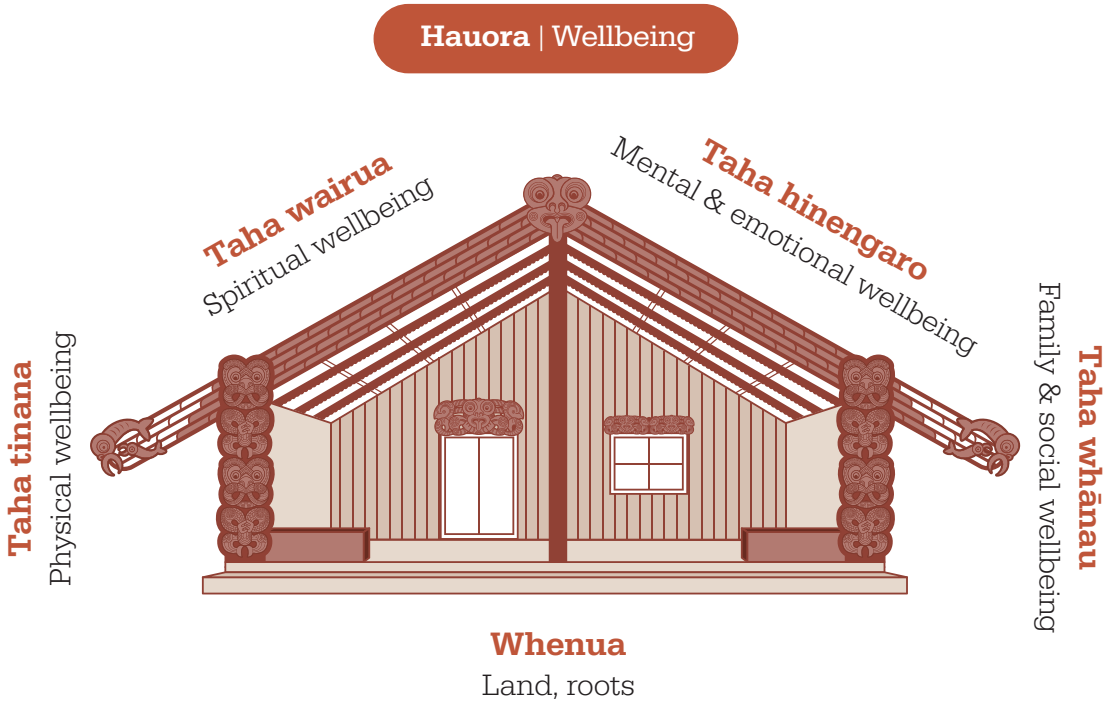
Te taha wairua

Our spiritual health



Whenua

The land we stand on is our wharenui's foundation – our roots, where we belong and feel safe



Developed by Sir Mason Durie

There are also other models used to encompass the total well-being of a person that may better meet the needs of yourself and your whānau. For further information see Mana Ake 'Cultural Models of Well-being'.

Something to think about...

How can I care for each important part of my life during this difficult time?

He toka tū moana, arā he toa rongonui

Your strength is like a rock that stands in raging waters

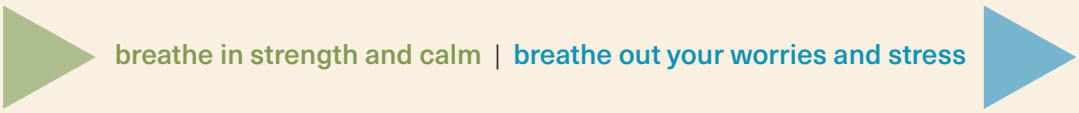
Tools for coping with stress

Breathe Easy

Breathing slowly and deeply helps reduce stress and calm anxiety. It increases our body's oxygen, slows the heart rate, reduces blood pressure, and releases body tensions. The more we pause to take slow, deep breaths, the more benefits we get.

1. Pause and notice how you are breathing right now. In stressful times we breathe faster and shallowly in our chest, rather than slowly and deeply in our belly.
2. Sit or lie comfortably. Relax and lower your shoulders. Maybe close your eyes.
3. Put one hand lightly on your chest and one on your belly.
4. Slowly breathe in through your nose, then hold that breath for a few seconds.
5. Purse your lips and slowly breathe out through your mouth, making a gentle whooshing sound, like blowing out a candle.
6. Now focus on breathing in a way that moves your belly gently in and out, not your chest. As you concentrate on doing this, the deeper your breathing will become.
7. Do this a few times. Inhale through your nose, pause, then exhale out through your mouth. Don't rush it.

Some people like to count as they breathe in, hold, and breathe out.
Aim to take longer to breathe out than you do to breathe in.



Try some 4-7-8 Breathing.

1. Breathe in slowly while you mentally count to four.
2. Hold that breath and count to seven.
3. Purse your lips and slowly blow out your breath while counting to eight.
4. Do this several times. It helps to practise.

There are many different breathing exercises to try.
Perhaps search online or at your local library for ideas.

Move

Physical exercise, whatever it is, is a stress reliever. It can boost your 'feel-good' endorphins, improve your mood, help distract you from worries, improve sleep, and increase overall health and wellbeing. Moving doesn't need to be complicated. You can exercise in brief bursts throughout the day if time is short. Brief walks, stretching, simple exercises, or dancing round the kitchen all help. There are many free at-home exercise ideas available on YouTube.

Do a Body Scan

Our bodies can hold a lot of tension.
This simple technique can help relax your body.

1. Sit quietly or lie down. Make yourself comfortable.
2. Take several slow, deep, belly breaths.
3. Begin at your feet and focus on each body part, one by one. Check how each part is feeling. Is it relaxed or tense?
4. Try squeezing and tightening each area at a time, just for a few moments, and then slowly let that tension go and relax it.
5. Gradually move up your body until your whole body feels more relaxed.

Be Mindful

In stressful times we can become preoccupied and overlook things, even what's happening around us. Mindfulness means tuning in to the present moment. It helps us gain some perspective by paying attention to where we are and how we are. 5,4,3,2,1 is a simple mindfulness exercise to try. Just pause first and notice where you are. Take a few slow, deep breaths, then slowly use your senses to find:

- 5 things **you can see**
- 4 things **you can touch**
- 3 things **you can hear**
- 2 things **you can smell**
- 1 thing **you can taste.**

Visualise - Use Your Imagination

Try using mental images to become more relaxed.
Focus your mind on calming and peaceful images, to reduce stress symptoms.

1. Imagine being somewhere relaxing and calm.
2. Take several slow, deep breaths and relax.
3. It may help to close your eyes.
4. Imagine all that you can see and hear in the imagined place.
   What can you taste or smell? How does your body feel in that place?
5. Spend some time taking it all in. When you feel ready,
   slowly return your mind to the present moment.

Some people enjoy using a guided visualisation, when a narrator describes a beautiful, calm scene and encourages you to mentally step into that place. Look out for guided visualisations online or on Apps promoting mental wellbeing.

> "I mentally drop by my happy place at least once a day. Afterwards I have a good stretch and feel more ready for whatever I am needed for." Ana

Get Close to Nature

Spending time in nature has been proven to help people decrease their levels of anxiety and stress. Even viewing scenes of nature in a book, a picture, or out a window can help. Nature's calm and steady presence reduces our heart rate, blood pressure, and body tension. It also lifts our spirit and mood. It brings feelings of happiness and calm.

Find some ways to enjoy being close to nature whenever you can:

- **Visit places that hold significance to you,** such as a place of good memories, or whānau–family land, mountain, river, or sea
- **Sit outside** – feel the breeze, safely enjoy the sun, notice what you see
- **Tune into what you can hear outside** – wind, birds, water, animals, cicadas
- **Walk outside near nature,** or drive somewhere beautiful
- **Sit near water** – by the sea, a river, a stream, a pond, or a lake
- **Look at books,** photos, or online to see some amazing nature
- **Put some flowers in a vase** and enjoy them
- **Have a few pot plants** around your home
- **Spend time in a garden**
- **Plant some bulbs** and watch them grow in spring
- **Grow some vegetables**
- **Put some nature art on your walls**
- **Visit a local zoo** or botanical gardens.



Using the help and support of others

Not every carer has a large whānau–family. Some carers have limited or no whānau–family nearby. However, no carer needs to be completely without support. Finding some help can make a big difference.

Different people or services may be able to help you in different ways, at different times. Often people you know will be willing to assist you if you ask, and some might directly offer their practical help.

Have a look at the kinds of people or organisations in the diagram below. Together, they can combine to circle you with support.

Use a circle of support. Everyone's circle will be different.



Those Closest to You

Such as whānau-family, good friends, pets

Others You Know and Trust

Such as other whānau–family, neighbours, other friends, co-workers, teammates, community contacts, mentors, cultural leaders, faith leaders

Available Health and Community Support

Such as, your local doctor (GP), the hospice, hospital, or nursing home healthcare team, other health workers, a counsellor or psychologist, a support group, a local community support agency, your lawyer or accountant, other helpful service providers

Who do you know and trust in your whānau–family and circle of friends? Who is closest to you? If you're a pet lover, don't forget your pet/s.

What about other people in your community you know and trust, such as neighbours, co-workers, teammates, mentors, cultural or faith contacts, or a community group?

And don't forget your local doctor (GP), district nurse, and the healthcare team helping the person you care for and supporting you. Think also about other local health services and community support providers.

Which of the different circles on the previous page would the people you've thought of fit into? Perhaps draw your own circle of support and write those people into it. It's encouraging to know who to reach out to if you need support.

Making the most of available support

At first, carers often prefer to do everything themselves because it feels easier. They might not know what help to ask for, or don't want to be a nuisance, or assume others are too busy. Some feel they 'should' be able to cope without help. However, this is an extraordinarily demanding time. Getting help, even with a few things, helps decrease stress and frees you to do other things. It makes good sense.

> "My sister said accepting her help was a gift I was giving her, but it was a win-win. We both gained. She asked if now wasn't the time to let others support me, when would be?" Mel

When people offer support, they are showing their care and concern. Being able to do something supportive for you, or for the unwell person, lets them feel they're helping to ease your journey.

- It's okay to share your ups and downs with those you trust. This helps them better understand how you're doing and what support you may need.
- Involve whānau–family in caring tasks. Delegate some responsibilities. Sometimes others may need to fill in for you or take over tasks you can't manage right now. Others won't always do things your way, but that's okay for now.
- Consult people you trust when problems arise. Fresh eyes can help see solutions.
- If you don't have whānau–family or good friends nearby, use technology to feel connected to them.
- Consider using helpful local services.

> "My son's mates would turn up. They did practical things for us and spent time with our son. They'll never know what a big difference they made." Casey

Think about what could help

It helps a lot if you tell people what you need, so they don't just assume or have to guess. List down what assistance could be helpful. Ask the unwell person for their suggestions too.

Things people might help with:		
Shopping or errands done	**Meals** cooked	Help with **housework**
Help **sorting out technology** at home	**Fixing** something	**Gardening** or lawn mowing
Looking after younger whānau–family members	**Transport** to and from appointments	Someone to **organise a roster** of helpers
Visitors to drop in and sit with the unwell person	**Someone to update** a wider circle of people with any news	**Advice** about organising personal affairs
Someone to **spend relaxing time with you** – to have coffee with, chat, go for a walk, watch TV together		

Coordinating offers of help

- Having a roster of helpers might be helpful. Perhaps ask someone to organise one.
- Put a list of jobs somewhere where it can be seen or shared online. It could list what needs doing so people could sign up for a task. This way everyone knows who's doing what and when.
- Keep a list of any people who have offered help and their contacts details.
- When accepting help, write down any key information the helper might need to know about.

Updating people with news you want to share

- Using technology makes this easier, such as using email, an answer phone message, or a social media group. Supporters appreciate an update and will understand using technology to do this.
- Perhaps ask someone trusted to be responsible for news updates, or to phone particular people in person.

See page 41 for tips on Managing Visitors.

> "You have a caring whānau around you and whānau *arohanui* [deep affection], *manaakitanga* [kindness], *tiakitanga* [guardianship, protection], *kotahitanga* [togetherness, solidarity, collective action], *wairuatanga* [Māori spirituality], *karakia* [prayers, incantations, chants], all those things. Together, they help to carry, not only the one person but the whole whānau through that whole process …"
> Kuia K, Mauri Mate, Hospice New Zealand

Some helpful links for carers

These links can connect you with useful carer support information and services. Different support may be available for different people's unique situations.

- Carers NZ

  Provides information, advice, learning, resources, and support for whānau–family carers across the country. Carers NZ Helpline 0800 777 797.

- Ministry of Social Development (MSD)

  A Guide for Carers He Aratohu mā ngā Kaitiaki.

- NZ Government Carers Link page

  You may be able to get money to help with caring for someone at home who has a disability, illness, or health problems because of old age, depending on your circumstances.

- Health New Zealand Te Whatu Ora

  Search for Carer Support Subsidy.

- Whaikaha – Ministry of Disabled People

  Respite options and services for those supporting someone with a serious disability related health condition.

- Age Concern

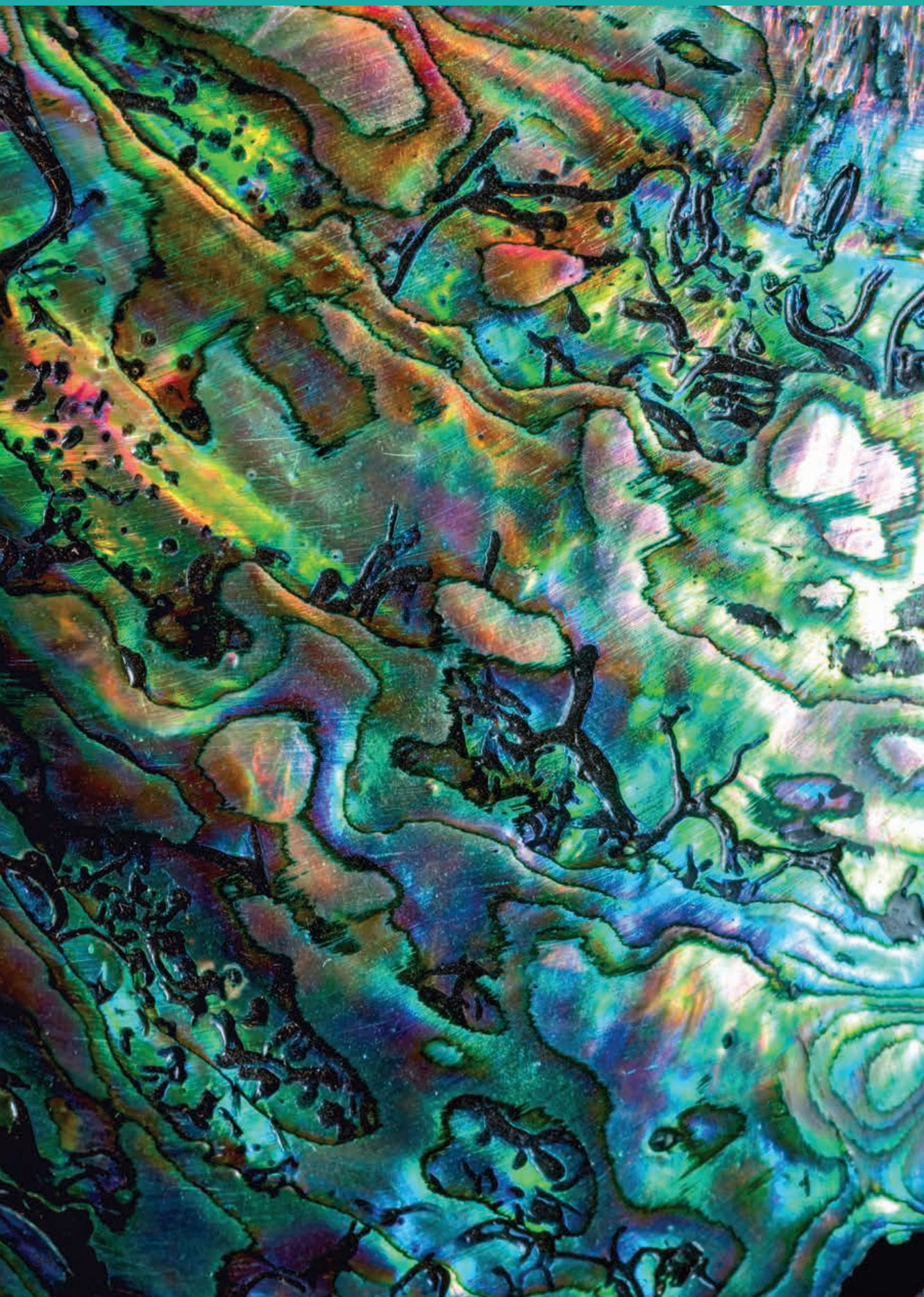
  Information for carers.

- Seniorline

  Click on the Support for Carers tab.

- MyCare

  An online carer matching service that aims to help carers find and access relief carers more easily. Call 0800 677 700.



Te Manaaki Tūroro

Caring for the Unwell Person

The person you're caring for may be independent and need little help, or they might need assistance with quite a few daily tasks. As their illness progresses, the kind of care and support they'll need is likely to change. Helping them to maintain their independence for as long as possible is important.

> "I want to help him enjoy his life as much as possible, right up until he dies. I know it won't be easy, but that's what I want to do." Lydia

What they may be going through

When a person hears they have a terminal illness, it's a lot to take in. It's common for people in this situation to experience a mix of emotions at different times, such as:

shocked | stunned | disbelieving | numb | upset
anxious | disappointed | pouri-sad | grieving | overwhelmed
angry | resentful | helpless | frustrated | resigned | accepting

Every person is different. Reactions aren't predictable and can change.

- Some people react very little at first because they feel stunned and numb. Reactions can start to come later. Others may experience immediate distress.
- Some may want to talk about it, but others don't, or won't.
- Some might want more information to better understand their situation and feel more in control of things. Others don't.
- Not every question can be easily answered. The uncertainty can be extremely unsettling.

- Many may find they're preoccupied by their situation and it's harder to concentrate or think clearly about other things.
- Many also experience physical reactions, like a tight chest, body aches, an upset stomach, dizziness, shaking, headaches, lost appetite, or poor sleep.
- Some may want to be near other people more, but others might prefer to be more on their own.
- Many have spiritual questions about life and death. Some instinctively draw on their values, beliefs, culture, or traditions to make sense of things. Others don't.

Witnessing the person's reactions to their situation can be very hard, especially when you're probably also managing your own reactions to the news. Gently check in with the person to see how they're doing in the hours and days after the news. Accept that wherever they're at, they'll need some time to process the situation in their own way.

Identifying their needs

Understanding the person's needs can help you to better understand what they're going through. A new day can sometimes bring different needs.

The healthcare team can help identify the unwell person's needs at different stages. They'll use their expertise and experience to talk with the person. They may then discuss the needs with you. Let them know about any needs they might have missed, which you have noticed.

These kinds of questions can help you focus on their changing needs:
What helps them feel comfortable and relaxed?
What could help them feel more in control of their situation?
What do they most enjoy? How can these things continue for as long as possible?
What or who do they like to have around them, or nearby?
Is there anything they might want to talk about? Who could they talk to?
What cultural or spiritual needs might need some support?
Are there decisions they need to make? What information or advice might they need?

Supporting their day-to-day care

Carers often say they learn new skills and knowledge as they provide care. For example, how to give someone medication, keep them comfortable, help them move around, or provide the food and drink they enjoy. You'll find you tune into the person's symptoms and needs more as they change from day to day. You will start to sense when more help may be needed.

- Enable the person to have as much control as possible. Becoming more dependent on others can be distressing. Do what you can to empower them, even with small choices.
- Assisting the unwell person to dress in usual clothes, look good, and be as independent as possible (even with some limitations) can help them feel positive about themselves. ▶ **See personal care** tips on pages 59-64.
- The person's emotions are likely to be up and down throughout this time. Your ongoing presence, emotional support, understanding, and encouragement will all help.
- Carers often spend a lot of time thinking, planning, and coming up with solutions. If you feel unsure about any aspect of providing care, ask the healthcare team or local doctor (GP). Check out the Hospice New Zealand website, or your local hospice's website, for helpful resources.
- It can be a relief to chat with other carers who've 'been there'. You can also swap tips and knowledge that might make things a bit easier. You may meet other carers when visiting a hospice, hospital, nursing home, or residential facility. Consider joining a carers' support group or online carers network.
- Don't expect too much of yourself. You have limits too. Treat yourself with the kindness you'd give a good friend. ▶ **See pages** 24-28 for stress busting tips.

Communicating well with the healthcare team

It's important for the unwell person to communicate well with their healthcare team. This helps their needs and wishes to be supported. You are likely to have a lot of interaction with the team yourself.

- Check that the healthcare team understands if the person is hard of hearing, non-verbal, or cannot communicate easily due to a disability. You may be able to help them communicate.
- There is no such thing as a silly question. Ask the team about anything you're feeling unsure about. Speak up if you or the unwell person ever need something explained again, or more information. If medical language is hard to follow, always ask what the terms mean. If you're at home, then hospices, hospitals, nursing homes, and residential facilities will have a phone number to call about any concerns.

- The unwell person will need to make choices about their treatment and ongoing care. The healthcare team will talk about their options. Some people decide to continue medical treatment to extend their life as long as possible, despite possible side effects or risks. Others prefer to protect their quality of life and choose not to continue treatment. Everyone is different. People will choose what they think is best for them and their situation. Encourage the person to ask for what they want and respect their choice.
  See also *Advance Care Planning* on page 78.
- You may find yourself becoming the unwell person's advocate if they become unable to speak for themselves. If you are one of several carers, decide together who will communicate with the team on the person's behalf.
- If the person is at home, check if your local doctor (GP) will make home visits when needed. If not, ask the healthcare team which doctor can. Check how the doctor likes to be contacted.
- The doctor (GP) might refer you to hospice or hospital palliative care specialists who can better explain medication side effects, offer more specialised treatment, and answer complex questions. Check who any specialist appointments are with and their purpose. Perhaps ask for copies of letters, results, or reports to be sent to you. It's okay to ask for a second opinion.
- A doctor's appointment is usually around 15 minutes.

Take a list of concerns or questions, such as:
What is the goal of this treatment, procedure, equipment, or medication?
What is important for us to know right now?
Might there be side effects?
Please explain what we can do if ...
How will we know when death is getting closer?

No one can exactly predict when death will happen. It's more realistic to talk about the signs to look for.

- Offer to be at appointments with the person, so information can be understood well, but respect their choice if they prefer to have private appointments.
- Consider taking notes at meetings to refer to later, or perhaps ask permission from the healthcare team to use a cell phone's voice recorder, or a similar device, so the discussion can be listened to again.

- It may be helpful to keep a handy notebook or file of information about the person's care and treatment. For example, medication given, appointments, paperwork, and healthcare team contacts.

Always draw the healthcare team's attention to any new needs or concerns. It's important to talk to them when extra care and help is needed.

Receiving updates on the person's health

As the unwell person's health condition progresses some new challenges may emerge, such as serious new symptoms, complications, or difficulties related to treatment or medication. For many carers, hearing this news can be a shock and a knock back. You may find you have similar reactions to when you first heard the person's terminal diagnosis. Again, it may take time to take it all in, and what this new reality means for the person you're caring for, and for you and your whānau–family. Intentionally caring for yourself well can help give you the strength and energy you need to cope, and to continue to support the unwell person as best you can as things change. ▶ **See pages** 18-33 for self-care tips.

Staying hopeful

Remaining hopeful is often important to people nearing the end of their life. Hope can mean different things for them at different times. At first, it may mean hoping to live 'normally' for as long as possible. Later, it might mean being optimistic about seeing special people, visiting treasured places, or achieving an important goal. As the days move on, the "hopes" can gradually change from larger, future-focused ones, like hoping to travel overseas for a holiday, to smaller more reachable ones, such as travelling locally to watch a sporting event or going to a cafe. Hope can mean positively working towards achieving something that will improve quality of life, like to sit in a chair with a view, go for a drive, or video call a relative.

You will probably find your own hopes will shift and change during this time too.

Hope helps people find some inner strength and resilience to cope, without hiding from difficult truths that must be faced. Look out for opportunities to support hopeful thinking. Reassure the unwell person you'll be there to help them through this time, and so will others, because not being alone can be one of the greatest hopes a person has.

Supporting their spiritual needs

A dying person often begins to reflect on their life and death. We all have a spiritual side. It often involves looking for the meaning and purpose of things. For some people, spirituality can mean having certain beliefs, a faith, or a religion and these may be expressed by following specific practices and traditions. For others, spirituality may be more of a personal belief system or philosophy of life.

As death nears, some people may struggle with spiritual questions, such as what happens after death or has their life matched up to their beliefs. Some might seek forgiveness for mistakes made. Spiritual distress can be very troubling for a dying person, and sometimes for their carer/s. In this situation, a palliative care team will often encourage a person to connect with a spiritual leader from their own faith, religion, culture, or philosophy to talk through any concerns. They might also offer the support of a Spiritual Carer, Chaplain, or Cultural Support Person who works with the team. Many people find that following certain rituals and practices, or just doing something that's symbolic for them, can be strength-giving, comforting, and extremely reassuring. Find ways to support your person's spiritual journey, even if you don't believe the things they do. Talk with them positively about their life story.

> "She asked for music to be played that calmed her. Even on bad days, she'd say it lifted her into a good place. She thought her next life would probably feel like that too." Andy

> "He found people dropping by to pray for him a huge comfort. So did I." Zara

If you are concerned about their mental health

Mental health may understandably be affected in such a challenging time, especially if the unwell person lives with an ongoing mental health condition. Anxiety can increase and make daily life seem harder. Existing mental symptoms may worsen and need more attention. Sometimes feeling very low, depressed, or experiencing other symptoms of mental distress, can be triggered by the person's illness, or be a side-effect of prescribed drugs. Suicidal thinking may increase for some people. Talk about any concerns you have with the healthcare team. Getting the right psychological care often helps a dying person feel better and has been shown to decrease their experience of pain.

Managing Visitors

Visitors can often be enjoyable and comforting, but there may be times when you or the person you're caring for finds hosting them is tiring, or inconvenient.

- Talk with the unwell person about their visitor preferences. Ask how often they'd like visitors, when, and for about how long. The healthcare team can provide advice on this too. Consider cultural differences. For example, some cultures, such as Māori and Pasifika peoples, might often want many more visitors than Tauiwi – Pakehā might, as having people near is considered a culturally important way of dealing with dying and death.
- Some carers find using a visitor roster system helpful. Perhaps ask someone else to organise this for you.
- Things can change daily, so swap contact details with visitors. If the unwell person can't manage visits, just let them know.
- A sign by the front door can let visitors know when it's convenient to visit. Perhaps leave a notepad and pen for messages. Consider leaving a recorded message on your phone asking people to leave a message if you can't always answer it. Perhaps ask someone else to regularly check for any messages.
- If you use email, messaging, or a social media group, consider sending a regular message to a group of whānau–family, and good friends, to update them on things. This avoids them needing to ring or visit. Perhaps ask someone else to do this for you.

Caring for your relationship

Your relationship with the unwell person may gradually change through this time. Your role might be different from before. For example, a parent could become the one cared for by their child. Sometimes an unwell person can begin to behave in unfamiliar ways. You may feel you don't 'recognise' them, because disease can sometimes change people's personalities as well as their bodies. This is normal, but not easy. Sometimes a relationship can deepen and you may feel closer, but the opposite can also happen. Understandably, the harshness and demands of dying can also sometimes strain relationships and give rise to tensions. In most relationships, there are moments of both these things. Try to make the most of your connection together, as best you can.

Communicating together

It's likely you'll be talking together a lot about big things and small things. Listening well is important. Listen for what's behind the person's words and actions. If you can, let them know what they mean to you. There may be times the person just doesn't feel like communicating at all. Encourage them to tell you when they'd rather have some quiet time, or time alone. You will learn to recognise their signals.

The illness may start to affect the person's ability to communicate and have full conversations. They may become confused, very sleepy, or unable to talk. Non-verbal communication can help, such as gestures, facial expressions, and gentle touch. Even people in a coma know when they're being touched and spoken to, so don't stop communicating with them. Look for subtle body messages, such as changes in breathing, in the look on their face, or what their body is doing. The person might be sending and receiving messages in these ways.

See *Talking about dying* on page 44.

> "We tried to make each day the best day it could be for us." Tina

> "I just tried to keep steady and constant no matter what. I'd take deep breaths in the tricky moments. Doing my best for her was what I could offer." Graham

If you shared a sexual relationship together

This will gradually change as the person becomes more unwell, but you can still explore ways to feel close to each other. The skin is one of the most sensual organs of the body. Gentle touch, such as massage, may be a tender and enjoyable way of sharing intimacy. Fear of hurting your partner during sex or intimate times is a common worry, so chat to your doctor or nurse about any fears you have in this area.

He taonga rongonui te aroha ki te tangata

Kindness towards others is a precious treasure



Te Kōrero mō te Ahua o te Mate

Talking About Dying

Many people find talking about death and dying difficult, but most dying people appreciate being free to talk about it honestly and openly. This gives opportunities to have meaningful conversations about the end of their life. It lets them share fears and worries, as well as their care and treatment preferences. It also lets them express what's most important to them before they die. This helps them make the most of their remaining time and reduces their stress.

> "When we got to talk honestly about her dying, she looked so relieved." Eddie

Some carers say they don't want to upset the person by talking about dying, so they avoid it. However, the unwell person has probably already been thinking a lot about what dying means for them. Talking about dying isn't usually just one conversation. There can be as many conversations about it as the person wants to have.

> "I didn't know how to start. A hospice nurse suggested having a simple question to kick things off, but my daughter just asked me if we could talk about what she'd like done when she died. The door was opened." Jackie

The person might want to tell you about their symptoms, or concerns, or have questions or requests. If they ask you if you think they're dying, perhaps say something simple, like "It does seem that your life is nearing its end, yes." Perhaps ask them to tell you more about what they're experiencing. They might say things you find hard to hear or disagree with. Try to respect what they say, and their need to say it, even if you see things differently.

You might like to view together the videos on the *Hospice New Zealand* website titled What is it like to die? and Meet Waana – realising the time has come.

See also the *Personal Stories* videos.

> "We talked things through, even about what dying might be like. Later it felt good knowing I'd done my best to let her express herself and say what she needed to say." Jana

Some dying people, or those close to them, don't want to talk about dying. It's their choice. Don't force them to. Let them know you'd be happy to talk if they ever want to. Sometimes a person might prefer not to talk with you but with someone else. Support them to find the right person for them. If you find you want to talk about death and dying yourself, ask the healthcare team who you could talk to, such as a Family Support Worker, Cultural Leader, Spiritual Carer, or Counsellor.

Palliative care specialist Dr Ira Byock suggests there are four important things a dying person often wants to communicate at the end of their life. Saying these, in their own way, helps them acknowledge their most important relationships, or mend them. They can help a person find peace of mind, especially if there have been ongoing hurts and tensions. They can be said more than once and in different ways. These are also things you might want to say to them, in your own way.

The four important things are: *I love you. Thank you. Please forgive me. I forgive you.*

If the ill person ever wants to tell you something important, try to listen well. Show you're listening to what they're saying. You don't always have to answer or respond immediately. Help them contact anyone else they might want to speak with or message. Doing this can help to relieve anxiety and fulfil their wishes.

Their end-of-life wishes can be thought through and noted down by using an *Advance Care Plan*, which is explained on page 78. ▶ **See also** the *Planning Ahead* section on page 77 about writing a Will, funeral preferences, and putting personal affairs in order.

If you would like to see some whānau video stories that reflect Māori caregiving values at the end-of-life, visit Te Ipu Aronui - see *Whānau Manaaki Family Caregivers*.



Tētahi Anga Māori ki te Manaaki i te Tangata i te Whakahemohemotanga

A Māori Approach to Caring for a Person at the End of Life

Ensuring the ill person has quality, holistic care is a priority wherever they are – at home, in a hospital, in residential care, or at hospice. Holistic care means caring for the whole person – physically (tinana), spiritually (wairua), mentally and emotionally (hinengaro), and for their environment (whenua) and relationships (whānau).

Your health team understands that providing care for a dying loved one is an important way for whānau to uphold the mana of their person. Whānau care can help their loved one to live as well as they can at the end of their lives. Whānau can support their person to prepare for their wairua (spirit) to leave the body and transition into the spiritual realm when the time comes.

Key Māori values can guide and strengthen whānau at this time include...



Wairuatanga
Honouring spirituality



Aroha
Compassion, love, empathy



Whanaungatanga
Valuing relationships and key connections



Manaakitanga
Caring for the prestige, status, or authority of the dying person



Kotahitanga
Building whānau unity, sharing the load, making decisions together

> "The body is perishing – but the wellness of the wairua (spirit) is so important at this time. It can feel more settled or rangimarie (peaceful) before death if the care is tika (correct)."
> Dr Tess Moeke-Maxwell (Newsroom interview, May 2021)

The importance of tikanga and kawa include...

The end of life is a time for observing certain tikanga (customs) and kawa (protocols). These are learned from mātauranga Māori (knowledge) passed down from tupuna (ancestors) through iwi, hapū, and whānau. Traditions can differ between regions.

Some whānau may want to closely observe tikanga and kawa, while others may not be as committed to that or unsure about what they involve. The thoughts and wishes of the dying person can help guide the whānau. It's important for whānau to talk about what is most culturally important to them and to find ways to prioritise these.

You may choose to contact...

- Whānau, hāpū and iwi
- Kaumatua (Māori elder)
- Rongoā Māori practitioner (traditional healing)
- Trusted spiritual leader
- Trusted advocate.

Some of the things you may choose to help uphold the mana of your person are...

- Whānau visiting
- Speaking te reo Māori
- Having a Kaumātua present or available to give support and guidance
- Observing tapu protocols and practices to identify what is sacred or restricted during this time
- Observing noa protocols and practices to lift the rules and restrictions of tapu at the right times
- Karakia (prayers)
- Waiata (songs, singing)
- Sharing kai (food)
- Visiting ancestral homes or tūrangawaewae, places where you and your whānau feel connected, empowered, and have a strong sense of belonging

- Taking special care of your person's taonga (treasured objects)
- Rongoā Māori (traditional healing) – **See** page 50
- Respecting tikanga Māori such as not using a pillow to sleep on if used elsewhere on the body
- Upholding protocols relating to removing, retaining, returning, or disposing of any body tissue or substances taken from the dying person, however small.

Things to remember

Hospices and medical professionals will support you as much as possible while accessing and meeting your cultural needs. Let your health team know how they can best support you. If your person's illness progresses beyond the capacity of your whānau to provide the required care at home, they will help you find options that have space for whānau to continue to contribute to the person's care wherever they are. Honouring death traditions can also bring together whānau pani (bereaved family) and provide comfort and support.

Helpful links

- Te Ipu Aronui is a website for Māori whānau caring for adults and kaumātua (older people) at end of life, and for their whānau. It provides support as you journey with someone who is dying.
- Hospices across Aotearoa are focusing on 'Mauri Mate: A Māori Palliative Care Framework for Hospices' to better support Māori accessing Palliative care and end-of-life care.

Kia Kaha, kia maia, kia manawanui

Be strong, be brave, be steadfast



Whauwhaupaku. Five-finger.
Pseudopanax arboreus.

He ringa nā Rongo, he ringa nā te aroha

The hands of peace are the hands of love

Ngā rongoā a te Māori i te whakahemohemotanga

Rongoā Healing – Māori Treatments at the End of Life

> "Rongoā Māori is a taonga. It is something that is highly valued, to be treasured, treated with the upmost care and respect."
> Rob McGowan (Pā Ropata), Rongoā Māori practitioner

Many elements work together to strengthen a person's sense of Mauri Ora. As you and your whānau walk together on the end-of-life journey, accessing rongoā is considered by many as essential for quality care.

You may draw strength from:

- Understanding of and connection to whakapapa (genealogy)
- Te ao Māori (connections with the Māori world)
- Kōrero Māori (talking together in Te Reo Māori)
- Respect for te taiao (the natural world)
- The oral sharing of knowledge.

You may choose to include:

- Rākau rongoā (native plant-based remedies)
- Mirimiri and romiromi to unblock physical, emotional, or spiritual blockages
- Karakia (prayer)
- Mahi wairua (spiritual healing work)
- Other, such as the telling of pūrākau (legends) or waiata (songs).

> "I have found the use of Rongoā Māori useful in many areas of my wellbeing. It not only engages with the physical, but also with my spiritual and mental wellbeing. My Rongoā practitioner is professional and personable, and most importantly she understands intuitively what I need… this is exactly what I need at this time of my life."
> (One patient's comment)

Who provides Rongoā Māori?

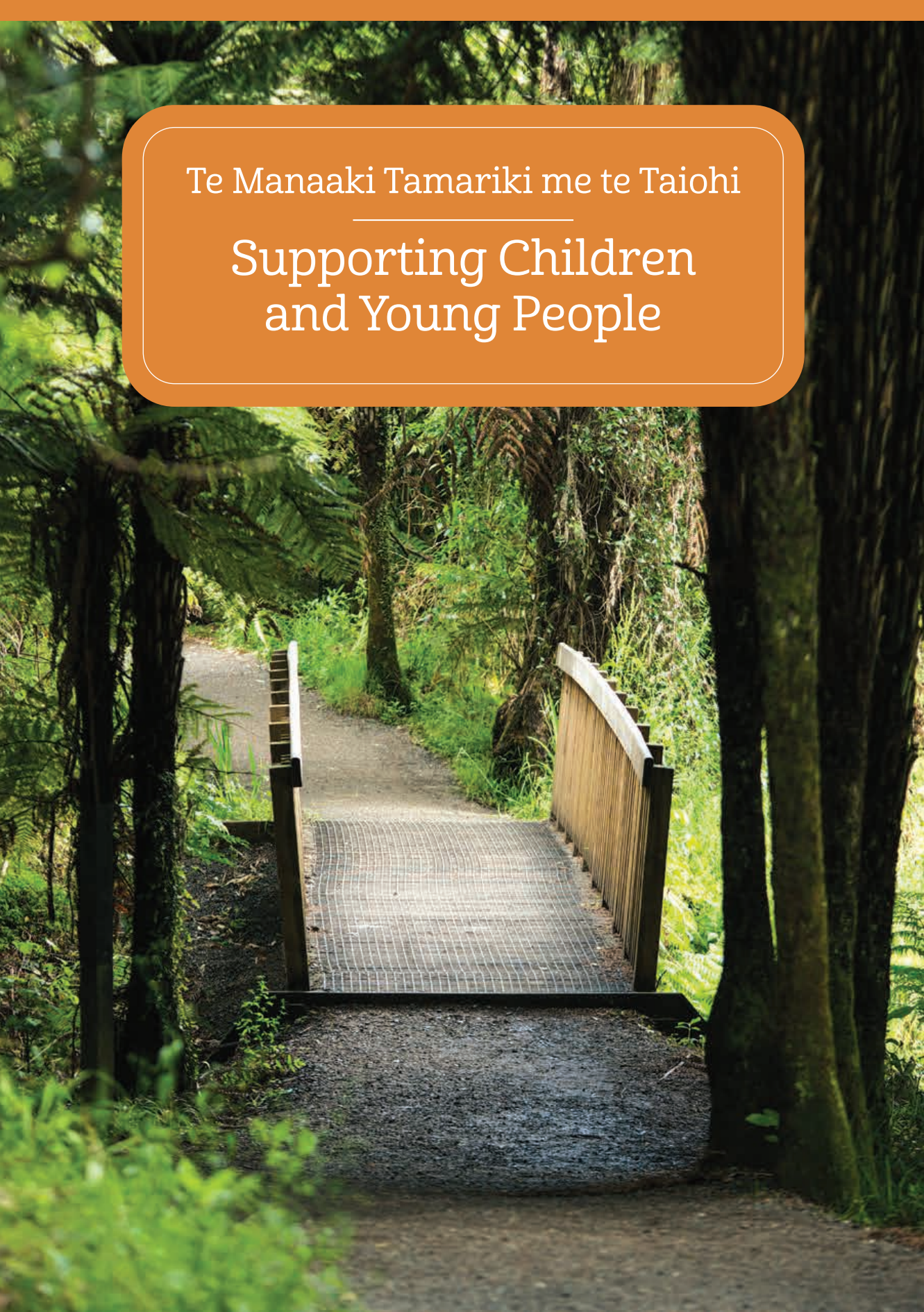
Experienced practitioners have knowledge and skills passed down to them from their Tūpuna, through their whānau, hapū, and iwi. These will vary regionally. To find a local practitioner, ask for recommendations from:

- Whānau and friends
- Local iwi leaders
- Any local Māori health services in your area
- Your health team
- Your local hospice.

ACC also provides a list of current practitioner names on their website.
These contact details can be used by anyone. Search *Rongoā Māori services.*

Things to remember

Hospices and medical professionals support the use of Rongoā Māori. Always let the unwell person's health team know that they're choosing to use Rongoā Māori. Also, tell the rongoā practitioner about their health situation and any medicines or treatments they're having, to make sure that any traditional healing methods being used don't unintentionally cause harmful side effects, or clash with other prescribed medicines or treatments being used. Share the positive benefits that are gained as this will ensure the best understanding and outcomes during this end-of-life journey.



Te Manaaki Tamariki me te Taiohi

Supporting Children and Young People

Everyone is affected when someone in their whānau–family has a terminal illness, even the youngest members.

Often tamariki–children and rangitahi–young people know more about what's happening than adults realise. They can sense adults' tensions and distress and notice new routines. They might overhear conversations or get told information by others. These things can be worrying and unsettling, whatever their age or stage. Talking to them with gentle honesty helps them to trust you and feel safe. Support them to understand what's happening, answer their questions as best you can, and comfort them through their different reactions.

- **Use simple, bite-sized pieces of information and words** they can understand. Just give basic details. Don't over explain. Talk somewhere comfortable and familiar. They might need information repeated, or to ask a question. Always answer honestly. They may ask questions when doing other things, like playing, having dinner, or as they get ready for bed. Follow their lead.
- **Young ones can be confused by phrases** like "going away" or "going to sleep". Instead, it's more helpful to use words like dying and death.
- **You may cry when you talk with them, but that's okay.** They might cry too. Tears are normal in sad times.
- **They'll each process things in their own way.** They'll often react in bursts, then return to normal activities. We can mistakenly think they aren't affected by what's happening.
- **Keep usual routines and activities going as much as possible**. It gives some certainty in uncertain times.
- **Give them some simple caregiving tasks** to let them feel they can help too and be part of things.
- **Being told they're loved, safe, and cared for is very important for them.** Let other caring adults know they may need some extra support, like their teacher, sports coach, or whānau–family, and good friends.
- **Check in with them regularly.** Update them on things. Ask how they're feeling. They might worry that they or others will die too, or that everything is their fault. Reassure them. Give opportunities to express what's inside, like talking together, being creative, or doing physical activities.

For more ideas see *"Supporting Children and Young People"* at Caring for someone at home on our *Hospice New Zealand* website.

> "We told them they each have an invisible string that goes from their heart to their Dad's heart, and it can never be broken – no matter where they are." Janey



Te Manaaki ki te Kāinga
- he Kupu Āwhina

Managing Care at Home – Practical Tips

Organising the house - a helpful checklist

Everyone's home situation is different. Each unwell person's care needs will also be different. Here is a checklist to help you organise the house to support the person's care, comfort, and safety – and yours. Expect that some things may need to be re-organised at different stages of the person's illness. If you're ever unsure about anything around the house, ask the healthcare team for advice.

1 Set up a space for the bed

Think about where the person is going to sleep or spend most of their time. If possible, talk about this together. Have a look at the space and what the options are. If you need help to move furniture, ask others you know or your healthcare team.

- ☐ **If the person can move around easily and safely from their bedroom**

  Think about setting up a comfortable chair or a day bed in the living room, ideally with a window view. Or have a comfortable chair in the garden. This gives them choices about where they'd like to be during the day.

- ☐ **If they can't get about easily and safely**

  Where's the best place for their bed? It might not be the bedroom, especially if it's on a second floor. They might like their bed set up somewhere near a bathroom. If they want to feel a part of everyday life, perhaps put their bed in the living area. This also gives more room around the bed for people to provide care for them.

2 Make the areas they will use comfortable, with important things nearby

- [ ] Think about the pillows and bed linen. Do you have what you need? Have you got spares for when you change the linen?
- [ ] Is there a bedside table, or a table on wheels that could be positioned over the bed? A table is useful for keeping meals, drinks, and other important things nearby, such as:
  - glasses or contact lens
  - phone
  - phone charger
  - television and radio controls
  - game controls
  - laptop or other devices
  - books, magazines
  - paper and pen
  - a favourite mug
  - a torch
  - a small rubbish bin or bag.
- [ ] A bedside drawer is handy for keeping more private things nearby.
- [ ] Would they like a container for snacks kept handy?
- [ ] Ask if there's anything they'd like you to put near them, like a loved blanket, artwork, or photo.
- [ ] Are there chairs near the bed for visitors? A few stools or bean bags can work too, or folding chairs that can be put away when not needed.
- [ ] Would they enjoy having a radio, music player, computer, tablet, gaming devices, or a television nearby? How can they best be set up? These things can provide comfort, entertainment, distraction, and a link with the outside world.
- [ ] Check the Wi-Fi connection works well.
- [ ] How can the person let you know when they need help? Organising this can help give you both some peace of mind. Set up your phone number on their phone, so they can text or call you. Or have a hand bell they can ring that you can hear from any part of the house. Using a cheap door alarm system, a set of two-way radios, or a baby alarm are also options.

- [ ] Think about safety. Reduce the risk of tripping and make getting around easier by removing any unnecessary furniture. Move floor rugs away from the bed. Tape down any necessary cords. Keep the bed space as clutter free as possible.
- [ ] If getting in or out of bed starts to be more difficult, ask your healthcare team about what specialised equipment can make it safer and easier.

3 Organising the bathroom and toilet

- [ ] Think of ways to adapt the bathroom and toilet to their needs. You may need to loan equipment such as shower chairs, raised toilet seats, bath stools, or toilet chairs. These can make showering and toileting easier. Consider making room near the bed for a toilet chair (commode) if the person can't get to the toilet easily. Ask your healthcare team about their recommendations.
- [ ] Consider fitting handrails or grab handles to make standing and sitting easier. For example, a grab handle can make it easier to sit down or get up from the toilet, or to step in and out of the shower.
- [ ] You could fit an inexpensive shower hose (with a handheld showerhead) onto bath or sink taps. This can make washing and bathing easier and allows a person to be sitting down.
- [ ] Switch from soap bars to pump bottles. Do they have a favourite type of body wash?
- [ ] Avoid slipping. Non-slip mats make floor surfaces safer, particularly when wet.
- [ ] A bathroom door can be made to swing out rather than in, to make access easier.

4 Consider safety when moving around

- [ ] If the person can get around, encourage them to get up for meals, use the toilet when needed, and walk to the bathroom for their shower. They might enjoy sitting in a porch or outside in the garden. In all these areas look for tripping and falling hazards. Clear clutter. Keep floors free of obstacles. If possible, repair or tape down holes or rips in carpet or lino. Move sharp furniture they could bump against. Keep corridors and rooms well-lit. Look for ways to keep them, and others, safe from accidents.
- [ ] Would installing a simple nightlight help the person see clearly when moving about at night?

- [ ] Check steps are well supported by a secure handrail or hand grips. Think about installing a light if they are in a dark area.
- [ ] Be seating friendly. Add pillows or cushions to low chairs and flat surfaces to provide comfortable seating options around the house. Which seat can the person use to remove or put on shoes from a comfortable position?
- [ ] Safety handrails or hand grips can be fitted anywhere in the house. Ask the person where they might find them useful.
- [ ] Ramps can be fitted up steps to make it easier for wheelchairs. Ask your healthcare team about this.
- [ ] Physiotherapists and occupational therapists on the healthcare team are skilled in reviewing the physical needs of the person you're caring for. They can suggest what will make the home safe for everyone.

5 Get any needed equipment and supplies ready

- [ ] Check if the healthcare team can suggest equipment or supplies to make things a bit easier. They can also advise how to get these and use them properly. For example, it might be a walking frame, walking stick, wheelchair, shower chair, pressure relieving products, or a table designed to sit over the top of the bed or chair. There are a wide variety of aids available.
- [ ] Decide where you'll store any medical equipment, care items, medications, or dressings so they are safe, handy, and out of the reach of any children. Perhaps clear out a drawer or cupboard for them.

6 Make some quiet space for you and others in the house

- [ ] Find an area to relax in yourself. This can give you and others at home some space away from the person's bed, so you can rest or have some private time.

7 Think about things you might need yourself

- [ ] Are there snacks or refreshing drinks you'd like to keep handy?
- [ ] Are there any supplies you need to keep handy?
- [ ] Check that wherever you plan to sleep will be comfortable.

- [ ] Look around the house. If furniture has been moved, is there anywhere you could bump into things or trip over cords? You need to keep safe too.
- [ ] Where will you keep a list of handy contacts or useful information?

GOT QUESTIONS?

If you're unsure about anything, ask the healthcare team for advice and help.

(This checklist is also available as a PDF to download from our website)

Providing personal care

Providing personal care means helping an unwell person with their personal hygiene, washing, toileting, dressing, and looking after their personal appearance. This supports their wellbeing and sense of dignity. It also decreases the risk of infection and helps prevent any pre-existing conditions from getting worse.

How much personal care you're willing to provide is your choice. Every carer's situation is different. You may be comfortable doing some things, but not others. Or you might simply be unable to do some tasks.

Ask your healthcare team, local doctor (GP), community nurse, or local hospice about any personal care assistance (or home care help) that may be available, depending on each person's unique circumstances. If the unwell person has a community services card, there may also be some domestic home care assistance they are eligible for. ▶ **See page** 33 for some helpful links.

If you're unsure about any of the following personal tasks, talk to your healthcare team.

Showering or washing

▶ Having a daily wash or shower can be refreshing but may be tiring. The person might not want a daily shower and that's okay. If a community nurse or personal care assistant is doing personal care, perhaps learn from them how to do things. Personal care assistants might not visit every day. If you're looking after personal care yourself, work out ways that work well for you and the unwell person.

▶ If movement causes pain, give prescribed pain relief about 30 minutes before their shower or wash.

Someone who is strong enough and able to move about can be helped to wash in a shower, bathtub, or sink. Put a shower chair on a nonslip mat in front of a sink, or in the shower or bath.

Maintaining a person's privacy is important and respectful. Ask or encourage the person to do what they can for themselves. They can ask for your help if they need it. If you are helping, use a sheet or towel to cover them when getting ready for a wash, shower, or bath.

Ensure the bathroom is at a comfortable temperature. Get together all the things you'll need before helping the person into the bathroom, such as clean clothes or pyjamas, soap, shampoo, facecloth, towel, lotion, and a seat to sit on to dry or dress.

Test the water before helping the person into the bath or shower. Warm the shower seat before they sit down. Do this by first placing a flannel on the seat and allowing warm shower water to run over it.

Allow the person to wash themselves as much as possible. You may need to help with their back, legs, feet, and genital area. Offer them help to get out of a shower. Place a towel on a dry seat. Cover their lower torso and upper legs with rest of the towel.

If a shower means heavy lifting, or needs too much of the person's energy, you can wash a person quite well in bed or on a chair. Using a bowl of warm water, facecloths, and towels to sponge and dry the person can work well. Your visiting nurse or personal care assistant can show you how to do this:

- Gather all the things you need, including a bowl for washing.
- If you have a high-low bed raise this, if possible, to lessen the strain on your back.
- Cover the person with a light sheet or blanket from the bed for warmth and privacy.
- Use a mild soap when sponging the skin, then rinse and dry it off as you go.

- Start at the face and work down towards the feet. Wash front and sides first, then help the person to lie on one side while you wash their back. Wash the genital area from front to back last. Only expose those parts of the body being washed.
- Washing is a good time to check the skin for signs of redness or rashes on the body. Talk to your healthcare team about any concerns.

Ask the person if they'd like to use any favourite scented soap or shower gel.

Skin care and massage

If the person spends a lot of time in bed or in a chair, check their skin every day. Look out for red areas, sore spots, or dryness, especially on the bottom, back, ears, heels, and elbows.

After washing can be a good time to try some gentle skin massage. Just use gentle strokes and light rubbing. Maybe use scented (or unscented) oils, lotions, and moisturising creams to massage dry skin and sore spots. Feet can get particularly dry.

Massage is often comforting. It helps keep skin soft and supple. Don't massage where the skin is infected or inflamed, around the stomach area, or if their legs have a clot (deep vein thrombosis). If you're unsure, check with your healthcare team.

Bed linen

Change the sheets as needed, without stressing yourself too much. Perhaps ask a visiting nurse to show you how to do this when the person is still in bed.

Perhaps move the top sheet to the bottom and put a clean one on top every day or two.

To protect the mattress from any soiling from incontinence, use a large towel or a bed pad over the bottom sheet. There are aids to help with ongoing incontinence. These are often inexpensive and often washable. Ask one of the healthcare team about these or contact Continence NZ for free, helpful advice on 0800 650 659.

Handling the person

The person may need help to move. Be aware that bending and twisting while lifting them could injure you. An occupational therapist, physiotherapist, or visiting nurse can teach you how to lift and move someone safely to avoid injuries. Look after yourself by learning the right way to do this.

Anyone who spends a lot of their time in bed must be moved regularly, usually every two hours during the day and once or twice at night. The nurse can recommend how often to turn the person you're caring for. If they're very sick and near death it may be better to move them less, or maybe not at all.

If the person has fallen and you don't think you can pick them up safely, cover them with a blanket and perhaps a pillow under their head. Call neighbours or whānau–family to help or call an ambulance on 111.

Mouth care

A dry mouth is a common problem. It's usually a result of medication or oxygen therapy. Applying vaseline, lanolin, or lip balm to their lips every few hours helps prevent and treat dry and cracked lips. Moist swabs are also available from a chemist or ask the healthcare team about them.

Try pineapple or feijoa juice, frozen pineapple chunks, ice cubes, or acid/sour lollies to encourage saliva production and to refresh their mouth.

- If the person can suck and swallow, small chips of ice will keep their mouth moist.
- If they're not eating or drinking, wipe their lips and tongue every hour or two during the day with a wet swab, and whenever you see to them at night. Iced water is usually the most comfortable and refreshing. Ask a nurse about swabs to use for this.
- People are more prone to oral infections when they can't swallow properly, and food gets left in their mouth. Check their mouth each day and keep it clean. Watch for infections, such as thrush, which looks like small white patches on the tongue, gums and lips. It can make a person's mouth very sore and eating difficult. Thrush is easily treated with regular mouth washing and prescribed drops, lozenges or tablets.
- If an ordinary toothbrush hurts too much, try a very soft one, or use mouth swabs or moistened gauze wrapped around your finger. Dip these in water. A nurse can advise about mouth swabs.
- You can use a pharmacy mouthwash or a weak solution of baking soda (half a teaspoon) and a pinch of salt in half a glass of lukewarm water. Ask the healthcare team for their advice.

Nail care and shaving

- Keep their nails cut and clean to avoid scratches. A podiatrist could trim hard and thickened toenails.
- A man may enjoy a daily shave. You can get the things ready for him to do it or do the shaving yourself. Ask a nurse or personal care assistant for any tips.

- A woman may like her legs and underarms gently shaved, or want her eyebrows shaped. She might also enjoy wearing some perfume or makeup. Ask her what she prefers.

Hair care

- Clean hair can make the world of difference to how someone feels. It's possible to wash someone's hair in bed. It just takes a plastic sheet, towels, a jug, and a bucket or bowl. Perhaps ask a visiting nurse or personal care assistant to show you how to do it. Other options are special shampoo caps available with infused shampoo product to make it convenient and easy, or shampoo wipes, or dry shampoo. Check your supermarket, chemist or online.

- It may be possible for the person to have their hair cut or styled at home. Hospices, hospitals, nursing homes, or residential facilities may know of hairdressers willing to come to do this.

Clothing

- Dress the person in comfortable clothes that are easily put on and taken off, and not tight. Clothes like track suits or t-shirts of soft stretchy material are much easier to deal with.

- Wearing nightclothes all day (unless they're very sick and in bed all the time) can emphasise a person's illness. Encourage the person to get dressed each day.

- Correct fitting shoes or slippers help prevent tripping or slipping.

- When a person becomes less mobile or unconscious, changing clothes can be difficult. Blouses, shirts, T-shirts, and night clothes can be cut down the centre back. This allows the same "look" from the front but makes them easier and quicker to change.

If the person has a disability or special care needs

A person may have unique issues and circumstances that make meeting their needs more challenging for their carer. Talk with the healthcare team about these. For example:

- Mobility difficulties
- Additional health conditions needing support or treatment
- Communication difficulties
- Difficulties with comprehension, affecting their ability to make informed decisions
- Unusual ways of expressing symptoms or distress
- Behavioural or mental health challenges.

Supporting a person with a disability or special needs of any kind can need some extra planning and perhaps some extra support provided.

Using special equipment

A range of equipment is available to support people to keep their independence, do daily tasks safely and more easily, and to continue to live at home. The healthcare team can advise on what may be needed, especially the team's occupational therapist. They will explain the equipment and how it can be made available. They will also support you to develop the skills to manage the equipment.

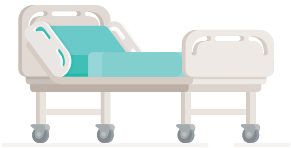
Practical equipment commonly used for people at end-of-life includes:



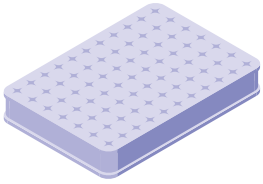
walking frame to enable independent walking



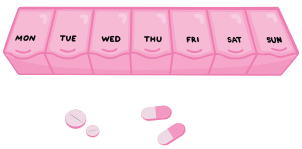
wheelchair to enable mobility



hospital bed that has safety sides and can be raised or lowered



pressure relieving devices to prevent bed sores, such as special mattresses, sheepskins, or cushions



medicine container to hold pills for each part of the day, at the correct dose



syringe driver (to slowly deliver medications under the skin) and container for used syringes or needles



shower chair



safety bath or shower handrails or hand grips



bath board to safely get in and out of the bath



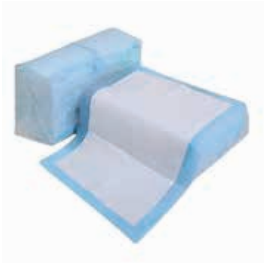
slide sheets to make it easier to move the person



commode (portable toilet that looks like a chair) or devices to enable toileting



urinary catheter (tube into the bladder for passing urine)



products to help if incontinence becomes an issue (loss of control over passing urine or bowel motions), including absorbent pads for a bed or chair

Giving medications

An important part of providing comfort and care is to provide medication that can prevent or help relieve any discomfort and suffering caused by the illness. This often involves a person taking multiple medications to treat the illness, and sometimes also the side-effects of treatments. Not everyone will need or want medication, but at some stage many people do find it helpful. Some people also choose to take vitamins, herbal medications, or other natural supplements.

It's important to keep track of what is being taken, why, and when. Safety is a top priority.

Tips to help you manage the medications and prevent any mistakes being made accidentally:

- When a doctor gives a prescription, check you understand what it's for, what it does, and about possible side effects. Check the dosage and how it should be given, such as with or without food, or at what time. Some medications should only be given when needed, such as for pain. Note down the instructions.

- Make sure the doctor knows about any non-prescription medications being taken, including supplements or natural products. This is to avoid any possible harmful effects from them interacting with prescribed medication. (It's helpful to know the healthcare team cannot report any illegal drug use, such as marijuana, but if they do know about it, it can help them prescribe for the person as carefully as possible.)
- Keep a list of the prescribed medications, as well as non-prescription items. Include any over-the-counter medications like antacids, supplements like vitamins, protein powders, herbs, or other natural products. Note down their name, the dosage being taken, and who prescribed or recommended it. Your healthcare team may provide a helpful chart for this. Keep your list or chart nearby for quick checking.
- Communicate well with other involved whānau–family members about why certain medications are being used and how. Understanding this better can help them feel less anxious or concerned about it.
- To avoid accidental mistakes, keep track of all medications in an organised way, such as keeping them all in the same place. Heat and light can change the chemical composition of some medicines, so most medicines are best stored in a cool, dark place.
- Try to organise the way you store your medicines so it's easy to tell them apart.
- When you collect a prescription, check it's got the right name on it, the right pills, and the right dosage. Ask the pharmacist or healthcare team if you have any questions about it.
- Watch out for when medications will run out and arrange another prescription, if needed. Take into consideration public holidays, and GP closures, as running out of medications over the holidays can lead to unnecessary stress.
- It may not always be easy for medication to be taken as prescribed. For example, a person with nausea, or who is finding swallowing difficult, may feel unable to take medicine by mouth. Always tell a nurse or doctor and they can explain the options to help solve this situation.
- The healthcare team will regularly look for signs that a person may be in pain or having distressing side-effects. Tell them about any signs you've noticed. These might include increased pain, a fever, nausea or vomiting, seizures, appetite changes, sleep changes, increased fatigue, increased anxiety, or mental confusion. There may need to be some medication changes.
- Medications can change, so return any unused or out-of-date medications to the pharmacy.

Natural therapies

Natural or complementary therapies may be used alongside or instead of treatments recommended by medical professionals. Below is a list of therapies that the person you are supporting might choose to include in their treatment and ongoing care:

Massage	Aromatherapy	Rongoā (Traditional Māori healing)
Cultural, traditional, and spiritual healing practices	Meditation	Visualisation
Relaxation	Therapeutic touch	Music therapy
Art therapy	Reiki	Reflexology

Ask if the hospice, hospital, nursing home, or residential facility offers any of these services, or if they have a list of local recommended natural therapy providers.

To get the best out of any therapy

- Tell the person's doctor which therapy the person wants to use in case this might stop prescription medicines or other treatments from working well.
- Also, let the therapist know details about prescribed medicines or treatments, so they can tailor the therapy to safely benefit the person as much as possible.
- If possible, look for registered and qualified natural or complementary therapists.
- Talk together with a therapist about how they can improve quality of life and what to expect from them. Check if there might be any possible side effects to look out for.
- Consider the cost of these therapies as a part of the overall budget.
- Avoid an unwell person feeling pressured to use a therapy. Always let it be their choice.

Providing Food and Drink

People with advanced illness often lose their appetite. Many things can affect it, such as tiredness, pain, nausea and vomiting, depression, sore dry mouth or throat, constipation, changes in taste, and diarrhoea. Things can be done about some of these causes, but it's likely the person will increasingly need different food than they have in the past.

A person's desire for certain foods, even for favourite food, can change. Be understanding if they change their mind about food they asked for and you've prepared.

Some useful tips:

- It's usually better to offer small meals throughout the day rather than big meals less often. Perhaps bring food when the person says they would like some or keep snacks handy for them.
- Maximise eating opportunities for when the person has the greatest amount of energy. This is often in the morning.
- Offer them a choice of small portions of savoury and sweet foods.
- Sometimes the smell of cooking may be unpleasant for them. Keep smells down by turning on the extractor fan or opening the windows.
- Ill people can have less sense of taste, so possibly offer them more tasty or spicy foods. Think of some traditional or favourite foods they might enjoy, such as kai moana – sea food.
- Add sauces or gravies to dry foods.
- Avoid tight clothing around the stomach area as this can feel both uncomfortable and affect appetite. Help a person to sit up before eating.
- Tell the visiting nurse or doctor if nausea is a problem. Medications to decrease nausea can be prescribed.
- Need to prepare some food quickly?
    - When you cook, freeze some small portions you can warm quickly in the oven or microwave.
    - Pre-packaged or canned food could be an option, such as soups, yoghurts, creamed rice, or custard.
    - Natural baby foods are a good way of having readily prepared small amounts of healthy food on hand in a variety of flavours. Some can be heated and mixed with a bit of milk or cream to make a delicious cup of soup.
- You can fortify food with dried milk, ice cream, eggs, honey, and dried food supplements to make it more nourishing.

- If the person can only manage fluids:
  - Soups and milky drinks can be tasty and enjoyable.
  - Specially fortified drinks (available from pharmacies or ask a nurse) can replace a whole meal and might be enjoyed more if chilled.
  - Freeze fruit juice onto a stick, which is especially enjoyable in hot weather.
- The feel of food's texture is important.
  - A person with a dry or sore mouth might prefer soft food.
  - If solid food is a problem, blend it or strain it through a sieve.
  - Make smoothies.
  - Keep each part of the meal separate, if possible, rather than blending it into a colourless mash.
- Try to make food look appetising for the person. Place small amounts on a small plate or bowl. Perhaps present it on a tray with a flower and a glass of something nice to drink.
- The person might still enjoy wine or other alcohol but check with their doctor first as alcohol should not be taken with some medicines.
- Many people enjoy eating while someone's with them, rather than on their own. Perhaps time meals so you can eat with the person, or just sit and have a drink or snack with them while they're eating. They may eat more with you there. It can be a good time to relax together.

Nutrition in the last stages of illness

It's normal for a person to lose interest in both fluids and food. Carers often worry that a person isn't drinking, but it's a natural part of the body's way of getting ready for death. Taking in less fluid prevents the build-up of saliva, which takes effort to swallow and can cause noisy breathing in the back of the throat, coughing, and possibly vomiting. Drinking less reduces the amount of urine the person must pass too. If you're worried about dehydration, talk to the healthcare team about it.

See page 62 for oral care tips if the person's mouth is dry and uncomfortable.

Remember to prepare food and drink for yourself too

Don't forget about your own needs. Eating healthy food and drink will help you keep well and have enough energy to do all you need to. Try to eat at regular mealtimes and eat enough. Keep hydrated by drinking water regularly during the day. When you're dehydrated you can feel even more tired, get headaches, get dizzy or light-headed, and experience brain fog.

If you prefer making the person's food yourself, then whānau–family could still bring meals or snacks for you. If they offer help, perhaps suggest they make food for the freezer or bring food in for you.

You may like to ask the healthcare team if they can refer you to a local meal delivery service, such as Meals on Wheels. There are also supermarkets and private companies that supply ready made meals that are reasonably priced.

Even if you are not hungry or can't face food, choose to eat something to keep your strength up. Try having soup or make a smoothie. Have some healthy snacks in your pantry and fridge, such as peanuts, cheese, crackers, easy to eat fruit, sandwiches, or snack bars. They can give you an energy boost. Maybe make yourself a snack tray and leave it in fridge to grab from "on the run" when you are busy.

Understanding and dealing with common palliative symptoms

Pain

Pain may increase as an illness progresses. Signs that pain is making a person uncomfortable or distressed include:

- Facial signs, such as frowning, grimacing, or wincing
- Groaning
- Stiffening or resisting body movement when being moved
- Restlessness or agitation
- A bloated tummy
- Vomiting, dry heaving, or repeated burping
- The person tells you they are in pain.

- Pain is naturally unwanted and creates anxiety, but it can usually be managed well with the pain relief options available today. The aim is to take doses of medication that give constant relief. Taking the right amount of the right painkillers regularly is the best way to prevent pain, rather than waiting until the pain starts or increases. Extra doses can then be taken if the regular dose isn't enough.
- Painkillers can be given in many ways, depending on a person's situation and preferences. For example, as tablets, syrups, suppositories, injections, or skin patches. As an illness progresses, it's also common for medication to be given through a sub-cutaneous injection. A small, very thin tube is placed under the skin and then taped to the skin.

Medication is injected through the tube by a machine called a pump or a syringe driver. This regularly delivers very small amounts of fluid medication through the tube at certain intervals, avoiding the need for regular injections. The tube can stay in place for several days before it needs replacing. The healthcare team can explain this more.

- Your doctor may prescribe morphine or other strong opioid medication. These drugs are the most common pain medication used in palliative care. Be reassured that their use for pain doesn't cause addiction or hasten death when used at the right dosage.
- Other medications, such as antidepressants, steroids, or milder painkillers, may also be used to help pain relief, along with strong analgesics. The person may need to take more than one drug to control their pain. Different drugs work in different ways. When some kinds are used together, they can have a shared effect that provides much better pain control.
- As well as their benefits, pain medication can have side effects. These might include constipation, nausea, vomiting, drowsiness, and confusion. Talk to the healthcare team about any side-effects that you notice.
- Pain can become greater when a person is experiencing a lot of stress and emotional turmoil. Being able to talk to someone about their fears and problems may help the person more than medication alone.

Constipation

Ill people often get constipated because they're not moving around much, eating as normal, or drinking much. Try to avoid constipation because it may make other symptoms worse, especially pain.

- Some mediations, like morphine, slow down bowel movements so people often need to take laxatives, which are medicines that stimulate bowels to get moving more. Encourage the person to take any prescribed laxatives regularly, drink plenty of fluids, and move about while they can. They may also like to ask the healthcare team about using some natural alternatives.
- Extra fibre will help people who are still eating fairly normally. Try vegetable soups and fruit (both of which can be puréed), wholemeal bread, or oat porridge. Some herbal teas can assist in relieving constipation as well. Ask the healthcare team for advice.
- Even when someone's eating very little, they should have a bowel motion at least every three days. It is important that bowel motions continue regularly. If they don't, suppositories or an enema may have to be given to help relieve their constipation. A nurse can explain these procedures.

Nausea and vomiting

Nausea and vomiting may be experienced due to certain medications, some diseases, or other medical problems. The healthcare team will investigate the cause and may prescribe medication to help.

Things that may help include:

- Fresh air
- Getting rid of any smells that might make nausea worse for the person, like cooking smells
- Changing body position
- Sipping soft drinks like lemonade, ginger ale
- Sipping herbal teas such as peppermint or ginger tea
- Eating kiwifruit
- Sucking peppermints
- Taking anti-nausea medications as prescribed before meals.

Weakness and tiredness

Weakness and tiredness are common and frustrating symptoms of advanced illness which are difficult to overcome. Using tonics or vitamins won't help much. If the person is anaemic, blood transfusions may help for a while. Although, as the illness progresses, they may spend more time in bed or in a chair, it's still valuable to get up and move around a bit.

Conserve energy by organising daily activities in a way that leaves energy to do the things that matter and bring enjoyment. Prioritise the activities that are the most important. Allow for rest periods/days between activities or visitors. It may help to use a calendar to plan activities and rest days.

See page 41 for tips on managing visitors.

Losing appetite and weight

It's common for a seriously ill person to lose their appetite. Eating less often leads to weight loss.

- **See page** 69 for tips on providing food and drink.
- Buying new clothes that fit, or altering ones they have, can help the person feel as comfortable as possible.
- If they have lost a lot of weight, they may feel the cold more than usual. Extra layers of clothes, a blanket, or more heating may be needed.

Confusion

Confusion or delirium may occur as an illness progresses. It might be caused by medication or changing body processes. A dying person may not always recognise people they know. They might misinterpret what's going on around them or what people are saying. They may have vivid daydreams, nightmares, hallucinations, or see people who are not physically present. They might become agitated or restless. They may try to do things they can't do any more, like getting out of bed when they need to go to the toilet. They may be in pain but be too confused to let you know.

- The healthcare team can help if confusion or restlessness becomes an increasing problem. For example, the person might have a full bladder that needs draining, or they might need medicine to make them more relaxed.
- Keep the person safe from falling or hurting themselves. Sit with them and talk about what they're going through and try to reassure them.
- If things are becoming too difficult, get in touch with the healthcare team as soon as possible.

Drowsiness

A person may become drowsier and spend more time asleep than awake. During this time, if they become a bit restless or more conscious, then it is time to change position. In the last few hours often there's no need to move them at all.

See also page 91 for Signs and Symptoms When Death is Close.

Insights from other carers

If you would like to see some whānau video stories that reflect Māori caregiving values at the end-of-life, visit Te Ipu Aronui.

When to call for extra help

It's always okay to contact the healthcare team or a local doctor (GP) when you need advice, help, or support. Write down their after-hours contact numbers in case help is needed during night hours.

Reach out for advice or help if:

- The person's pain has increased
- The current medication doesn't ease the pain
- Symptoms are becoming extreme
- A serious new symptom or side effect has started
- The unwell person is very distressed
- You are not coping well yourself with your carer responsibilities right now and need more support.



Te Whakamahere
Planning Ahead

Planning ahead involves thinking about what's most important. If practical issues are discussed early, a person's needs and requests can be well supported throughout their palliative journey, and after they die.

Supporting a person to organise their personal affairs is important. When their choices have been made about any financial, property, or legal matters, and their final wishes have been expressed and fully understood, it can decrease their anxiety and bring a sense of relief.

> "There was a lot to talk through. We took it step by step. He felt much better knowing he'd organised things as much as he could. I did too." Carrie

In this section we provide a range of practical information to think about.

You might also like to visit the government website, Te Hokinga ā Wairua – End of Life Service. It guides a person through key tasks before death, including planning and organising personal affairs. It also offers the option to create, record, and access a personal plan online. Sometimes people prefer not to think about practical matters at all and let others sort things out for them. Everyone is different.

Advance Care Planning (ACP)

Advance Care Planning (ACP) is when a person thinks about and plans for their future healthcare and treatment, including during end-of-life care. ACP better prepares the person, their whānau–family, their carer/s, and their healthcare team for what the future might hold. Like writing a Will, or appointing an enduring power of attorney, having an ACP is a practical part of end-of-life planning.

- ACP encourages people to look at what is important to them, their values and beliefs, and what practical decisions may need to be made if they become unable to speak for themselves.
- ACP gives a person some control about the kind of care and treatment they would be happy with, or not. It helps them better understand the sorts of health situations they may need to make choices about. It can be reassuring for them to know key people will be informed about their preferences, especially if they become unable to speak for themselves. Anyone can make an ACP at any time. It's important to do, even if it's just been discussed and hasn't been written down.
- During the ACP process, people often find it helpful to talk with their healthcare team and to whānau–family and others close to them. Some people also talk with their lawyer.
- There are some important questions to think about, such as:
  - *How do you feel about different treatment options?*
    e.g. chemotherapy, antibiotics, pain relief, or going to hospital if needed
  - *Who do you want caring for you? Who do you not want?*
  - *Who do you want speaking on your behalf on health matters if you're unable to?*
- *Whenua ki te Whenua* – ***the advance care guide for whānau*** is a practical, free New Zealand guide to help people to make their own Advance Care Plan. It suggests ways to record any decisions made and how to let others know what they are. It is available in both English and Te Reo.

  The Advance Care Plan website offers:

  - A digital version of My Advance Care Plan that can be completed online and emailed to a person's healthcare professionals, and to their whānau–family and others of their choice, such as their lawyer.
  - A PDF copy of the guide to download.
  - Information on how to order a hard copy of it, at no cost. Or you can ask your local doctor (GP) for a copy, or the healthcare team at a hospice, or hospital, nursing home, or residential facility.

- It's important to keep an ACP up-to-date and to make any changes necessary if, at any time, a person decides to organise their future care differently.
- Carers find having an ACP in place reassures them that any decisions made during end-of-life care are what the ill person wanted, especially if they're unable to speak for themselves. An ACP helps decrease carer stress. It also helps lessen any anxiety or regrets after the person has died.
- It is a good idea for you to also have your own ACP. No one can predict if or when they may have a health crisis themselves and need care.

Possible organ or tissue donation

A terminally ill person may have an interest in donating their organs or tissue after they die, but it's not always possible. Ask them to discuss this with their doctor. If a donation is possible, encourage them to tell their healthcare team and whānau–family they want to be a donor. This can be a sensitive issue. In the event of their death, their closest family members will be asked if they agree with the donation and to complete a written consent form. Knowing the person's own wishes can help a lot.

A Do Not Resuscitate Order (DNR)

A do-not-resuscitate order (a DNR) is a legal document. In it a person formally chooses not to have cardiopulmonary resuscitation (CPR) if it's required in a serious medical situation. A DNR allows a person to have a natural death. It is a personal choice, not a whānau–family choice. The person can also state their wishes about this in an Advance Care Plan (ACP). ▶ **See page** 78. Be aware that some palliative care providers have a policy of not resuscitating terminally ill people, so check this with your healthcare team.

Organising personal documents

The person you are caring for may want to organise their personal affairs themselves or to get some help, from you or others. You both may find these tips from other carers helpful:

- Gather important documents in one safe place to be easy to find and refer to. Such as a written Will, their IRD number, any beneficiary information, insurance policies, Powers of Attorney, any Advance Care Plan (ACP), birth certificate, or the person's parents' names and dates of birth. (Whānau – family information will be needed later for a death certificate.) Instructions about wishes for their farewell, preferences for cremation and burial, or any pre-paid funeral arrangements made also need to be kept handy. Tell key people where the important documents are, such as a lawyer or future executor of the person's Will.
- List the person's financial or property assets. Note where important paper or digital documents relating to them are and list where each asset is kept. For example, property or land owned, life insurance policies, assets in bank accounts, safety deposit boxes, or held by a lawyer (such as valuable jewellery), investments, KiwiSaver or other superannuation funds, any shares or bonds, or any valuation or provenance paperwork for assets like house, art, antiques, or cars.
- Check life insurance premium payments and policy beneficiary clauses are up to date.
- Make a list of any money owed and to whom, such as mortgages or other loans.
- Check the person's Will is up to date. Help them get it updated with any future changes.
- A bank will freeze a deceased customer's individual accounts when they are notified of their death. This includes accounts, credit cards, loans, and any term deposits. The bank will then only take instructions from the authorised executor of the person's estate. However, joint accounts are not usually frozen. So, before a person dies, they may wish to set up a joint account with, for example, their spouse or partner, or a separate account in a trusted person's name. This provides some money for those closest to them to use without delay, such as for funeral costs. Encourage them to talk to their bank about this.
- Make a list of people and organisations the person is connected with and their contact details. This will make contacting them easier, if you need to.
- List any online accounts or subscriptions the person has, including email and social media accounts. Having usernames and passwords kept securely enables them to be closed down when the person is ready to, or after their death.
- List where any personal heritage documents or treasured heirlooms are and what the person would like to have done with them. This can also be noted in their Will.

Financial Matters

Planning financially can decrease an ill person's level of anxiety and uncertainty. They can talk directly with their bank and other financial organisations about their situation and ask their advice, or perhaps you could do this together.

- Visit the website Sorted for helpful information about different money matters.
- Free budgeting advice is available through Money Talks around the country.
- Some local whānau–family support organisations may offer budgeting support services.
- Registered Financial Advisors are also available. See the FMA website for details.

Some financial support might be available:

- If a person had to stop work because of their health condition, contact Work and Income about a possible *Supported Living Payment.*
- A person may be able to withdraw some, or all, of their KiwiSaver or other Superannuation Fund savings early for health reasons. Ask the provider about this.
- Check any insurance policies to see if they offer pay-outs when an illness or condition has become terminal, such as Life Insurance, Health insurance, or Employment Insurance. Check also if there is a funeral insurance policy in place.
- Some funeral homes and service providers offer discounts if the person who died was a SuperGold Card holder. Ask about this.
- A New Zealand veteran can apply for a lump sum payment if they have a terminal medical condition that is accepted as service related. Contact Veterans Affairs.

Enduring Powers of Attorney (EPA)

An Enduring Power of Attorney (EPA) is a legal document allowing a chosen person to make important decisions on someone's behalf when they no longer can. This helps make sure the unwell person's best interests will be well looked after.

There are two types of Enduring Power of Attorney:

A Personal Care and Welfare EPA

- This gives the named person the right to make legal decisions about another person's personal care and welfare. For example, about health treatment or who will care for them and where. It gets activated when a doctor legally verifies that the unwell person is unable to make their own decisions.

- Only one person can be appointed as a personal care and welfare attorney, but who this is can be legally changed at any time. Ideally it would be someone who knows the person's health situation and who understands their treatment and care preferences. (Preferences can be listed in an ACP. ▶ **See page** 78.
- Choosing someone trusted and reliable who will act on the person's behalf and in their best interests, and who is willing to do this, is very important. It helps if they live in New Zealand, as this makes their role a lot easier.

A Property EPA

- This gives the named person the right to make legal and other decisions about another person's financial affairs, property, and assets.
- A Property EPA will state when it can be activated – either immediately with the unwell person's agreement, or when a doctor legally verifies that person is unable to make their own decisions.
- There can be more than one property attorney appointed. Who they are can be legally changed at any time. If more than one person is appointed, they must consult with each other regularly. Property attorney/s might be a relative, a close friend, or a lawyer. Having a lawyer will mean paying a fee for work done, but it does provide legal expertise that can be very helpful.
- As above, choosing someone trusted and reliable who will act on the person's behalf and in their best interests, and who is willing to do this, is very important. It helps if they live in New Zealand, as this makes role a lot easier.

When no EPA is set up

When someone becomes unable to manage their own personal and financial affairs and no EPA is in place, whānau–family can apply to the Family Court to appoint a property manager to look after matters for them. Contact a lawyer, or for free legal advice about this contact your nearest Community Law Centre.

To set up an EPA

You can set up an EPA through a lawyer or trustee corporation, such as the Public Trust. It involves someone explaining what the EPA allows, to check it is understood, then a form being signed and witnessed for each EPA. Free legal advice about this is also available through your nearest Community Law Centre.

Writing or updating a Will

A Will is a legal document that makes sure a person's wishes are legally carried out after they die. It makes clear what will happen to a person's property and possessions, and how they want any dependants to be looked after, such as children.

A person's will can include:

- *what will happen to all their finances, property, and possessions (their estate)*
- *who they want to look after any children or dependents they have*
- *who they want to carry out their wishes – an executor*
- *what they want to happen to their body – e.g. burial or cremation, and where.*

- If the unwell person already has a Will, encourage them to check it's up to date so their wishes are correctly recorded.
- A person can write a Will themselves if they follow the proper legal steps. There are DIY kits available online, but there are risks that it may not be done correctly, making a Will invalid. If a person is unsure about the process, or has a complicated estate, it may be wisest to get help from a lawyer or trustee organisation, such as the Public Trust. Ask trusted whānau–family about recommended lawyers or see a list of local lawyers on the New Zealand Law Society website. The Community Law website offers information about making or updating a Will.
- When choosing an executor or executors to carry the wishes stated in the Will and distributing their estate, naming someone trusted and reliable who is willing to do this is important. Often it is a relative, a close friend, or a lawyer who brings their legal expertise. ▶ **See** next section.

If a person dies without a Will?

The process for managing someone's estate when there is no Will in place is longer and more complex than if there is a Will. This is called an intestacy or dying intestate. New Zealand law sets out how a person's estate will be handed out in this situation. It may or may not be how the person would have wanted it to happen, so making a legal, valid Will avoids this and decreases stress for whānau–family.

For more information

Speak with a lawyer, or the Community Law website offers free detailed legal advice on many aspects of Will making, including DIY Wills. Search Wills.

Executors of the person's estate

An executor is the person named and appointed in a Will to be responsible for managing and distributing the Will-maker's money and property after they die, according to their instructions in the Will.

- This is a legal responsibility. Whoever is chosen is being trusted to take this responsibility seriously and to do it well.
- There can be more than one executor chosen, but they must communicate together.
- It's a good idea to ask the person first, to avoid them refusing the role later.
- A lawyer or trustee organisation, such as the Public Trust, can give advice to executors.

Information about making a Will is on the previous page.

Guardianship for any tamariki–children or rangitahi–young people

A terminally ill parent can name a person in their Will (or another formal legal document) to be the testamentary guardian of their children after they die. There may be more than one guardian named.

Testamentary guardians have the responsibility of supporting a child's development and helping to make the important decisions in a child's life. However, they don't automatically have the legal right to provide day-to-day care for them. If they want to be involved in the child's day-to-day care, they must apply to the Family Court.

It is important to talk with a lawyer about this choice because it can get complicated in some situations. You can also find helpful information at Community Law. Search ***Guardians.***

Decisions about what will happen to the person's body

A person can state how they want their body cared for after they die. This helps whānau–family know exactly what their wishes are.

A person may choose to:

- Have some cultural traditions or spiritual practices followed
- Donate body organs or tissue
  ▶ **See** Organ and Tissue Donation on page 79
- Bequest (donate) their body to medical science (arrange before death by contacting Auckland University or Otago University – search Bequesting human body on their websites)
- Be embalmed
- Not use embalming (consider using cooling methods until the day of the funeral – ask a funeral director)
- Have certain people prepare their body
- Be dressed in certain clothes or jewellery, or have make up or hair done in a certain way
- Have their body to be viewed by others after death
- Be cremated or buried (traditionally or naturally)
- Be buried or cremated with special items, such as photos, letters, or treasured belongings
- Be buried, or their ashes put, in a particular place.

Letting whānau–family know what's been decided is very important. A person might like to write their wishes down and give a copy of them to whānau–family they trust, or to their lawyer. They can also note these wishes in their Will (page 83) or in an Advance Care Plan (ACP) ▶ **See page** 78.

Planning a farewell

A Funeral or Memorial Service

When there is a casket at the gathering, it is commonly called a *funeral service*. Without a casket, or when the ashes are present in a container, it is usually called a *memorial service*.

These are times to celebrate and remember the life of someone who's died. They give whānau–family, good friends, and communities an opportunity to say goodbye to them and support each other in their grief. Arrangements can be made to have a farewell at the time that most suits the whānau–family, and perhaps to record or stream the event digitally for those who cannot attend in person.

A service or gathering can involve many elements or be very simple. It can be held in a building, in a home, or outside. There are many choices available. Different people want different things. There is no legal requirement to hold a funeral or memorial gathering. Some people don't want any formal gathering, although whānau–family will often still get together in their own ways to grieve together and remember the person.

When a person pre-plans the kind of farewell they would like, there are different things to think about and decide. For example, if they'd like a traditional funeral or something different, where they'd like a gathering to be held, who they would like to lead it, and if they'd like certain things to happen at it. Some people like to plan the music they want played or what will be read at it. My Life, My Farewell is a free booklet the *Funeral Directors Association New Zealand (FDANZ)* offers to help people who pre-plan their own farewell. It is available for download on their website or ask for a copy at your local FDANZ accredited funeral home.

Using a Funeral Director or Celebrant

Often a terminally ill person will choose to meet with a funeral director or celebrant (who leads the farewell) to talk things through. They can help the person think of ways to make their farewell how they want it to be. Discussing costs is also important. A funeral director can explain ways to keep costs as low as possible. Some people prefer to prepay for their farewell, if they can, or they might have funeral insurance.

If you're using a funeral director, they can make sure all the correct paperwork is completed and legal requirements fulfilled, including registering the death and obtaining a death certificate.

- ***To find a funeral director:***
  Ask others who they recommend or see the FDANZ website.
- ***To find a celebrant:***
  Ask others who they recommend, visit Celebrants Aotearoa (Celebrants Association of New Zealand) or look online for local celebrants. Check the celebrant is a member of a registered association.

Choosing to organise the funeral, burial, or cremation independently

When organising a funeral, cremation, or burial, there is no legal requirement to use a funeral director. There are resources available to help people plan this independently. If a Funeral Director isn't used, all the legal requirements and documents for burial or cremation must be checked so they are correct and in order. Someone will also need to register the death and get confirmation of the cause of death.

- DIY Funeral is a not-for-profit New Zealand information website outlining what you will need to know about.
- You must complete the correct application forms to use local cremation and burial services. You can get these from the local council which runs the cemetery or crematorium facilities, either online or from their office.

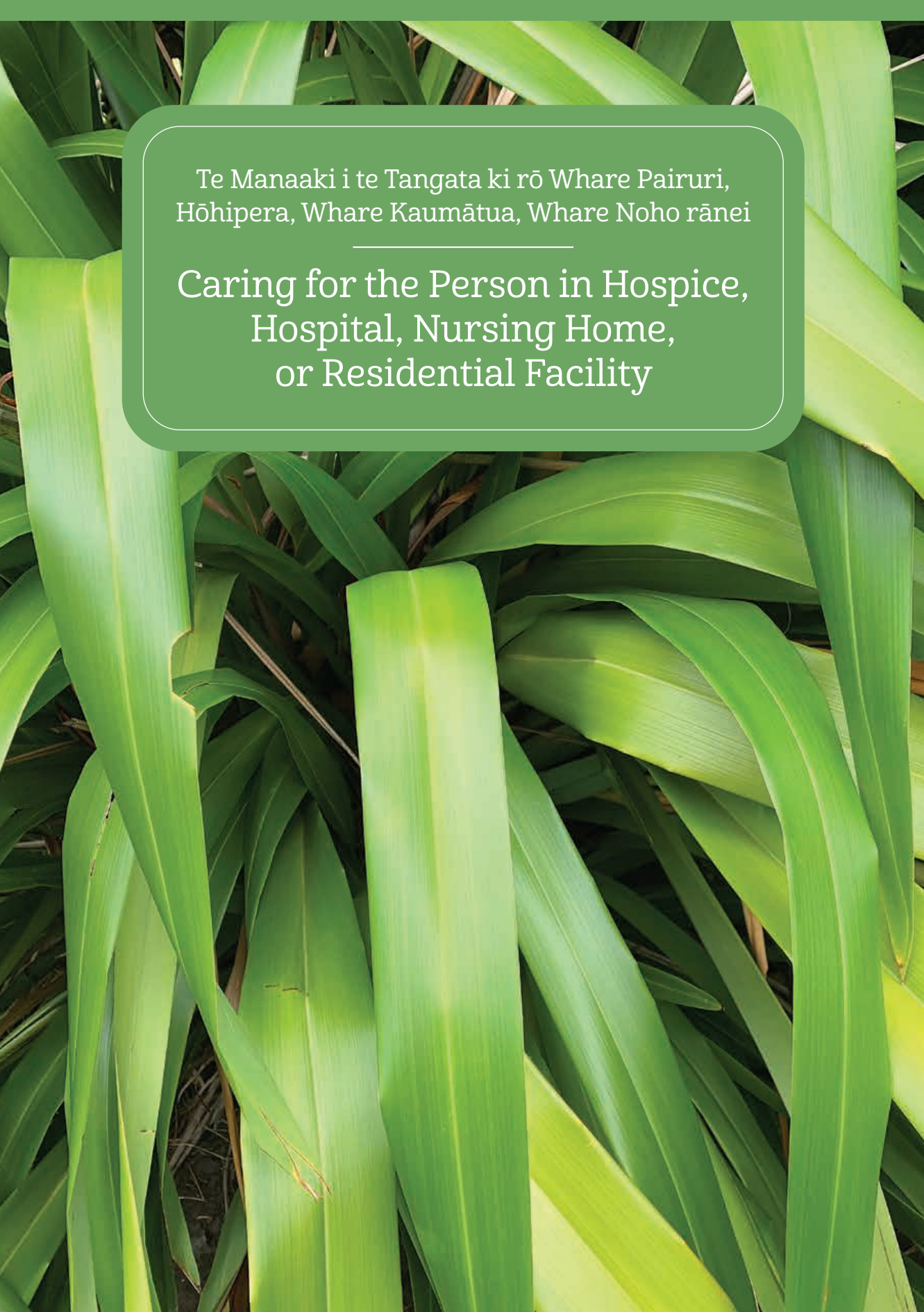
A Tangihana

If someone is Māori, they and their whānau may want to think about how they will use the traditional process of tangihanga or tangi. This is a time for whānau and their communities to gather and grieve and mourn together for the person who has died. Traditional rituals are followed from the time of death until the body is buried. Tangihanga practices can be different depending on where a person is from. Perhaps talk about what will happen with whānau or a local Kaumātua, who can give advice. If there is uncertainty about a person's whakapapa, a Kaumātua can also advise on that.

A person can search for the contact details of their iwi, hapū, or marae using Te Kāhui Māngai - a directory of iwi, hapū and Māori organisations.

Other cultural or religious traditions

Different cultures and religions respond to death and grief in their own unique ways. They often also approach farewells differently. It's helpful for a person to understand the protocols or traditions they would like respected. If advice or help with understanding cultural or religious requirements is needed, contact local religious or cultural leaders, or ask a funeral director to link you with one. There is a helpful range of differing customs and religious protocols relating to death outlined at www.amemorytree.co.nz . Search Customs.



Te Manaaki i te Tangata ki rō Whare Pairuri, Hōhipera, Whare Kaumātua, Whare Noho rānei

Caring for the Person in Hospice, Hospital, Nursing Home, or Residential Facility

A terminally ill person may be admitted into a hospice inpatient unit, hospital, nursing home, or residential facility to receive specialist palliative care. In this situation, their carer/s are still considered an important part of their support team. You can continue to provide care, just in a different place and in different ways.

Sometimes a person may be admitted because their choice to stay at home has not been working out so well, or because their carer has become unwell or needs some time out and respite from their duties.

> "When she was admitted I could catch my breath, rest, unwind a bit, and sleep through the night undisturbed. Those few days were so helpful. They made a big difference to how I was feeling and helped me get some energy back." Leo

If you'd like to, talk with the healthcare team about ways you can still help provide care. For example:

- Helping the ill person communicate with the nurse or doctor if they're finding it difficult
- Providing details of prescription and non-prescription medications or supplements being taken
- Advising the healthcare team if an Advance Care Plan (ACP) is in place and providing a copy
- Bringing things from home that might be requested or needed
- Helping the person to eat or drink regularly
- Keeping the person company
- Providing emotional support and encouragement
- Organising phone calls, video calls, or messaging with whānau–family or others
- Coordinating visitors, so they come at convenient times (▶ **See page** 41)
- Letting the healthcare team know of any cultural or spiritual needs the person has
- Talking with the healthcare team about any different care needed if they are discharged back home.



Te Manaaki i roto i Ngā Rā me Ngā Haora Whakamutunga

Caring in the Final Days and Hours of Life

Death usually comes gradually and naturally when someone has an advanced illness. It's impossible to predict the actual time of death, but doctors and nurses can give you an idea of the span of time the person has left. Even then, they can be wrong.

If a person has an Advance Care Plan in place, or shared with you or others any details about certain things they want as death draws close, this is the time to support those wishes as best you can. For example, they want certain music to be played, or certain people to be with them. They may have asked a trusted spiritual leader or cultural elder to visit to lead prayers or traditional practices.

Knowing common signs and symptoms of the dying process that people may experience in their final days or hours of life may help you feel better prepared. The person you're caring for may show some or all of the signs and symptoms explained below, or ones not listed here. Talk with the healthcare team about any questions you have.

Signs and symptoms when death is close

- **Not eating or drinking**

  As a person gets very close to dying their body doesn't need food and fluid to function. They are likely to lose all interest in food and drink, but this is normal. They no longer feel hunger or thirst. They may lose the ability to taste or swallow. Don't try to give them drinks or food at this stage. Liquid may collect at the back of their throat, which may become uncomfortable.

- **Confusion and Agitation**

  The person may become more disoriented, restless, or agitated in their last 24 to 48 hours. They may:

  - Move around in a restless or agitated manner
  - Try to get out of bed
  - Cry or call out, or say strange things
  - See, hear, or experience things that others don't, such as talking to someone not seen in the room.

  It can be hard to watch the person going through this process. Try reassuring them by talking calmly, saying who you are, and letting them know you're there. Avoid making sudden noises. Constant touching might be disturbing for them, so try just very gently holding their hand. Playing their favourite music may help to calm them at this time.

- **Vision and hearing**

  The person may get a faraway, glazed look in their eye. They don't seem to focus on anything, and when resting their eyes might not close all the way. Leaving a soft side light on may help. Hearing may not be as clear as it was, but it's considered to be the last sense to be lost. Encourage quiet conversation so the person knows others are there, but avoid them hearing any distressing conversations, such as whānau–family arguing. Many dying people relax more hearing calm music and quiet singing. This also gives any people present a way to participate in the moment.

- **Fever**

  Some people may have a high body temperature as death draws nearer. A doctor may prescribe a medication for this, but you could also try using a cool cloth on the person's forehead or behind their neck. Perhaps put a gentle cooling fan on. Check clothing or bedding isn't too hot for them.

- **Incontinence**

  People may lose control of urination and bowel movements (incontinence). Usually, a decision is made about using incontinence products or catheters to help the situation and provide dignity.

- **Sleep**

  The person may sleep most of the time, perhaps even all the time. They may not wake easily. As hearing is usually the last sense to be lost, keep speaking to them. Tell them who you are and who else is there, and explaining what you are doing. This is both reassuring and calming for them.

- **An energy surge**

  Some people experience a short surge in energy in their final hours or days. This could last from a few minutes to several hours. A person may be more alert and aware of things, want to talk more, or be interested in eating or drinking. This is a good time to be with them to enjoy the time together.

- **Breathing**

  A shortness of breath or more difficulty breathing is common. Try raising the top of the bed, open a window, use a dehumidifier, or have a fan to circulate air in the room. Prescribed medications may help relieve the sense of breathlessness.

  When a person gets closer to dying, their breathing pattern will often change:

  - Longer pauses between breaths
  - Deep rapid breathing
  - Shallow rapid breathing.

  Sometimes when the person is taking their last breaths they might seem to grimace. This isn't because they're uncomfortable. It's just the muscles in their body and face contracting and relaxing.

- **A Rattling Sound**

  As the person finds it harder to swallow, saliva and fluid secretions may collect in the back of their throat and upper chest. It might cause coughing and even sound like choking. There might be a rattling or gurgling noise when they breathe, sometimes called the 'death rattle'. This can be hard to witness but it's normal and doesn't mean the person is uncomfortable. Sometimes raising the top of the bed with pillows helps. Their doctor may prescribe medication to try to help reduce the secretions.

- **Skin changes**

  The person's skin may become pale or clammy. As death gets close, the person's skin will be cool to the touch. The base of their feet, fingernails and toenails, palms of the hands, and the area around their mouth may become bluish in colour. As the blood starts to circulate more slowly around their body, the skin might also look patchy, mottled, or dark in places. Their face may be pale and their nose cold. There's no need to put on extra bedding. This may make them restless. Depending on the room temperature, a sheet and light blanket should be enough.

- **Withdrawal**

  The person may gradually withdraw more and more into themselves. As death comes close, gentle touch and the caring, loving, compassionate presence of others nearby can be a great reassurance.

How to tell when the person has died

- Their breathing completely stops.
- Their chest stops moving up and down.
- They will have no heartbeat or pulse, or reflexes.
- They don't respond to your voice.
- Their eyes are fixed, their pupils are dilated. (Sometimes their eyelids stay open.)
- Their jaw relaxes. (Sometimes their mouth stays open.)
- They may have lost control of urination and bowel movements.

What to do if the person dies at home

You don't have to do anything straight away. You can just be present with the person and, when you can, inform those whānau–family who need to be told.

There's no need to call the police or an ambulance immediately. You will need to tell your local doctor (GP) or hospice or hospital healthcare team, because a doctor will need to prepare a death certificate. You will also need to let your chosen funeral director know if you are using one. If the death happens at night and you are comfortable being at home with the deceased person, make these contacts in the morning.

The time immediately after a death can be a very special time. Many carers say it helped to sit with the person and reflect. Naturally, it can be an emotional time, but many say it's also a time of quietness and peace. There is no need to rush things.

> "It was quiet and still. It was over. I felt all kinds of things at once – sadness, gratitude, relief, helplessness. I even felt some shock, though we knew death had been close. We sat with them for two or three hours, not speaking much and sometimes singing. It wasn't planned, but just what we needed to do." Annie

- Phone your healthcare team if you need help or advice at this time.
- Cover them only with a light sheet. Make sure electric blankets and heaters are off and the room is kept cool. A fan can help. You may like to lie the person on their back with their head and chest raised slightly on pillows and their hands on their chest. You can roll up a small towel to tuck under their chin and close their mouth.

- You may be alone or have whānau–family, a close friend, a Kaumātua, or a spiritual or cultural leader with you. (You could earlier ask someone to be ready at short notice.) You might choose to invite others to visit to pay their respects at this time or prefer to keep it a more private time for a little longer.
- This is a time to follow any last requests, such as any cultural or spiritual traditions or practices, that the person wanted followed. This might include washing them, dressing them, or positioning their body in a special way. Important prayers may be said.
- When you're ready to, contact the funeral director if you are using one. They can usually come fairly soon if this is what you choose. The funeral director will make an appointment with you and the whānau–family at another time to talk to you about arrangements.
- If you haven't already arranged a funeral director, ask others who they recommend or see the FDANZ website listing.
- If you are choosing not to use a funeral director, ▶ **See page** 87 for information.



Ka Mate Mai ana te Tangata

After the Person has Died

Some important tasks

Some key things need to happen after the person has died. If you need support to do them, consider asking help from a whānau–family member or a close friend. It can be harder to focus when you are grieving.

- A death must be registered with Births, Deaths and Marriages (BDM) within three working days of the person's burial or cremation. It's free to register a death. A funeral director will usually do this and request a formal death certificate. If a funeral director isn't being used, someone will need to register the death with Births, Deaths and Marriages, using the required form.
- A formal death certificate usually takes around 10 days after the death is registered. Banks, insurance companies, and other organisations may ask to see copies of the deceased person's death certificate. For example, before a bank account is unfrozen and funds released, or an insurance pay-out is made. The person's Executor/s will also need to have a copy. It can be helpful to make several copies of the certificate to have ready, if needed.
- Contact the deceased person's lawyer and/or executor/s after their burial or cremation. It is important not to put this off in case there are any issues with the Will. You might be the executor yourself. Seeing a lawyer can assist you to be clear about all you need to do to settle the person's estate and see their wishes followed. It can be a big job.
- If you are not an executor, ask the executor/s if there are any tasks you need to do, or to help them with. For example, giving them any documents or information they need.
- If you shared a bank account with the person who has died, visit your bank to arrange the transfer of money from joint ownership to single ownership.

- Any joint insurance policies, joint service agreements, or joint memberships will need to be closed or changed to your name only. Make a list and work through them, step by step.
- Make a list of other things that may need to be done. Who needs to be contacted? What needs sorting? There is usually no need to rush these, and you can ask others to help.

When your caring for the person ends, there will naturally be big changes for you. Grieving isn't easy either, so pace yourself. Take plenty of time to rest when you can.
▶ **See pages** 98-101 about coping with grief.

Grieving your loss

After the person's death there may be a great sense of loss. Carers often say they felt great relief when the person's suffering ended. Some say that even though the death was expected, the reality of it was still a shock.

> "I felt exhausted but also restless. Most of all, I felt relieved her journey was complete. So much changed for me because my daily routine and energy had been so focused on supporting her." Arnie

> "When it happened, even though I knew it would, it still kind of shocked me. I'd never seen anyone die before. It was hard to believe it." Anne

Grief is a normal, natural process after a loss. It's different for everyone and takes the time it needs to take. Allow yourself to grieve in your own way. Gradually, most people find the full impact of grief starts to ease up, although their connection and bond with the person who has died continues to stay with them.

Grief often affects people more than they expect.
Grief reactions are normal, but don't always feel like it.

Grief brings an unpredictable mix of strong emotions that come and go, like sadness, deep sorrow, relief, regrets, helplessness, anxiety, anger, or loneliness. Some people find they're emotionally numb or it may take time for grief feelings to begin. Others find the emotional pain is immediate and intense. Everyone's emotions are so different and changeable. Happiness and gratitude might also be in the mix. For example, if the death was managed peacefully or some special moments were shared together beforehand. Many carers say they found grief was emotionally draining and exhausting for quite some time.

Mentally it might be harder to concentrate on other things. You might feel distracted or be more forgetful. Going over things in your mind may make falling asleep more difficult. If you found what happened traumatic, you may find yourself replaying difficult memories in your mind or having bad dreams.

> "When I first went back to work, I kept forgetting things. I found focusing during meetings difficult. I also had some tearful days." Tony

Physical grief reactions can include deep tiredness, body tension and muscle aching, a tight chest, nausea, appetite changes, losing or gaining weight, headaches, being more tearful or unable to cry, or sleeping more or less than usual. Grief also lowers immunity, so people often find they're more likely to pick up a virus. Due to increased distraction, bereaved people can be more prone to having accidents.

> "I thought grief was just about emotions, but it was very physical for me. My body ached, my stomach churned, and I was shaky. I couldn't eat much. I found it so hard to sleep." Arya

You may want to spend time alone or be with other people more. You might like to talk about what's happened or avoid talking about it completely. You might like to go to social events or choose not to. Most people find they experience a blend of these things at different times. The kindness of others can be supportive, although sometimes too many offers, questions, or comments from others may get a bit overwhelming.

If your relationship with the person was a complicated one, perhaps with some difficult history, grief may feel a bit complicated. That's normal too. There are no rules about how grief should feel.

Some people may find reassurance and strength from spiritual and cultural beliefs, others might consider spiritual ideas for the first time, or prefer not to at all. Some may sense the presence of the person who has died and find that comforting.

> "Yes, I was grieving, but so were my kids. For me, supporting them came first. I parked my grief to one side until I knew they felt loved and comforted and cared for. Only then did my own grief really roll in." Elei

Make the most of any hospice or hospital bereavement support services

Hospices and many hospitals offer bereavement support, including grief information, counselling, or support groups. Some funeral directors or local support agencies also offer this. Ask what's available. See if these services might be helpful for you and others in your whānau–family.

What can help during grief?

Look after yourself well - eat healthy, drink water, rest, get some exercise

Keep up a daily routine

Give yourself permission to grieve in your own way

Take it a day at a time - don't rush

Express what's inside - write it down, create, make something, dance, sing, make a playlist

Put off any major decisions for now

Expect waves of grief at times - they're normal

Spend time in nature

Let yourself grieve - let it take the time it needs to take

Connect with others regularly

Be kind to yourself - treat yourself like you'd treat a good friend

Talk to someone you trust

Reach out for help if you need it - don't hesitate

Make time for good memories

Accept offers of help and support if this might make things easier for you

Learn more about grief - chat to others or read about it. It helps to know it's a natural process that's gradually helping you adjust to your loss.

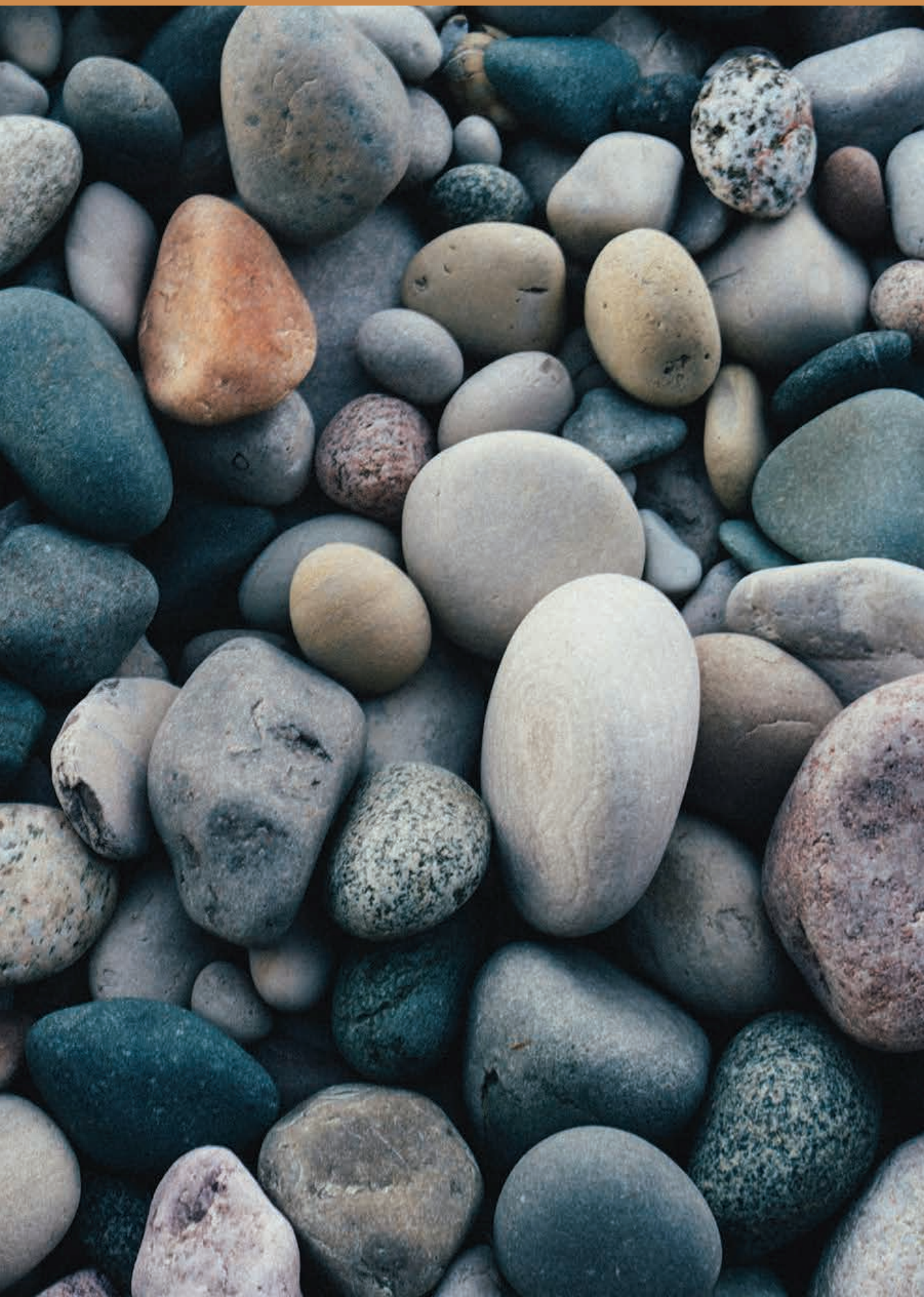
If grief gets hard to manage

For some people, grief can become very difficult to cope with. If your grief reactions don't ease with time, or they get worse, or they are seriously disrupting your daily life, talk with your doctor (GP), a counsellor, a community support agency, or someone wise you trust. For example, if you're still experiencing acute distress, not sleeping, experiencing flashbacks, or think you may be depressed. Reaching out helps you get the support you need to get through this intense time.

Gradually moving forward

Bereaved people don't just 'get over' their loss. They build their life out around it, bit by bit. Your loss, and caring for the person who has died, will always be a part of your story. You can continue to remember them and sense an ongoing bond with them. Gradually, you will move forward.

> "I couldn't imagine life without my son. It was incredibly hard at the start, but here I am now and I'm doing okay. I'm grateful for our time with him in those last days. It wasn't exactly easy, but important to do. I am now trying to make the most of life, as best I can, like he wanted me to." Sandy



Glossary of Terms

There may be some terms and phrases used in in Palliative Care services that are new to you. This simple glossary explains some commonly used ones. Some other terms are explained when they are used in the Guide.

It's always okay to ask one of the healthcare team or your local doctor (GP) about any word or phrase you don't know the meaning of.

Advance Care Planning (ACP)

When a person thinks about and plans for their future healthcare and treatment, including during their final days. ▶ **See page** 78.

Allied Health Professional

A health professional with specialised expertise who works alongside others with different specialist knowledge. For example, a dietitian, pharmacist, or physiotherapist working alongside a doctor or nurse.

Anticipatory Grief

When a person's anticipated death already causes a sense of loss, sadness, and grief.

Bereavement

The time after someone's death when we experience grief and express it in our own ways. We can grieve alone or with others. It is often a time for cultural or spiritual rituals that help people find meaning.

Capacity /Mental Capacity

A person's ability to make decisions based on having good understanding of the situation, knowing the relevant facts, being able to weigh up all the information, and then communicate their decisions clearly.

Carer

A person who providing ongoing personal support and assistance to someone due to their health and/or disability situation. Often a member of the person's whānau–family or close friend. ▶ **See page** 11.

Comorbidity

When a person has more than one health condition at the same time.

Constipation

When a person has uncomfortable, painful, or infrequent bowel movements.

Continued...

Death

Occurs when all the body's vital functions stop, including heartbeat, breathing, and brain activity.

Delirium

A fast change in a person's mental abilities, causing confused thinking, a lack of awareness of what's happening around them, and possible agitation. Can develop over hours or days.

Dignity

Being worthy of respect and having value.

Do Not Resuscitate Order (DNR)

This is a legal document in which a person chooses not to be resuscitated, which means helped to breathe again if their breathing or heartbeat stops. ▶ **See page** 79.

Dysphagia

Difficulty swallowing.

Dyspnea

Shortness of breath, difficulty breathing, perhaps changes in breathing pattern.

End-of-life

This phase begins when it becomes clear a person's death is drawing near. ▶ **See page** 91.

End-of-Life Care

This refers caring for the physical, psychological, social, spiritual, and practical needs of palliative patients, and their carers. It focuses on providing specialised and compassionate support as death draws near, in the final days and hours, and after the person has died.

Grief / Grieving

This is a natural response to loss and different for everyone. People experience a mix of physical, emotional, mental, social, and spiritual reactions to their loss which can, at times, be strong and demanding to cope with. Grief helps people gradually adjust to living after their loss. ▶ **See page** 98.

Home Medical Equipment

Supplies and equipment to support a patient's needs at home, such as a hospital bed, wheelchair, lifting equipment, or a bedside commode. ▶ **See page** 65.

Hallucinations

False or confused sensory experiences (sights, sounds or touch) interpreted as real.

Healthcare Team

Health professionals working together to support a patient and their whānau–family. ▶ **See page** 8.

Holistic Care

Care that responds to all of a person's needs - physical, psychological, spiritual, cultural, social, and practical. It means care is for the whole person.

Home Care / Personal Care Assistance

Services provided in the home, such as showering, or house cleaning.

Hospice

A community organisation specialising in providing free specialist palliative care for whoever needs it, wherever it is needed, for as long as it's needed. Hospice Care is about a compassionate

approach to caring, not a building. It is a community-based service.
▶ **See page** 7.

Inpatient Unit (IPU)

This is where care and treatment are provided in a local hospice or hospital.

Life Limiting (or terminal) Illness or Condition

A health situation that cannot be cured and will eventually cause death.

Multidisciplinary Team (MDT)

A group of health, allied health, and other support professionals who collaborate to effectively meet the care needs of a patient and their whānau–family.

Natural or Complementary Therapies

Therapies used alongside or instead of treatments recommended by medical professionals, for comfort and the relief of symptoms. E.g. massage, rongoā, or meditation. ▶ **See page** 68.

Oedema

An excess of fluid in body which causes swelling and may be very uncomfortable or painful.

Palliative Care

Provides compassionate, holistic support for a person nearing the end of their life. It aims to maintain the person's quality of life, or even improve it, as much as possible. It provides comfort, manages symptoms, relieves pain, and assists the person to die with dignity. Palliative care includes supporting the person's whānau–family.

Prognosis

A medical opinion, based on medical experience, of how a person's health condition will progress.

Pain Relief

Providing treatment or therapy to reduce, manage, or eliminate pain as much as possible.

Respite Care

Respite is a period of rest and recovery for carers. It can be provided for regular short periods, such as for a few hours or overnight in an inpatient unit, so that the carer can take some time for their own needs.

Spiritual Care

Support for the inner person and their personal values and beliefs as they deal with the life questions and internal challenges they're facing. Provided by a spiritual carer, chaplain, or cultural or faith representative.

Symptoms

A feeling or reaction a patient experiences that indicates illness, pain, psychological distress, or loss of function. Symptom management means working to relieve symptoms as much as possible.

Whānau–Family

Those the patient considers closest to them, which may include members of immediate family, extended family, or friends who are considered family.

If you are interested in more terms, including Te Reo Māori terms used in palliative care services, please see the Health New Zealand Te Whatu Ora website.

Your healthcare team contact list

This list of contacts is for you to fill in. It indicates some of the roles that may be in your healthcare team. Keep it updated and somewhere handy.

Their Role	Hospice
Name/s	
Contact Details	

Their Role	Hospital
Name/s	
Contact Details	

Their Role	Residential Facility (nursing home, rest home)
Name/s	
Contact Details	

Their Role	Local Doctor (GP)
Name/s	
Contact Details	

Their Role	Nursing Service
Name/s	
Contact Details	

Their Role	Pharmacist
Name/s	
Contact Details	

Their Role	Specialist Nurse
Name/s	
Contact Details	

Their Role	Palliative Care Doctor
Name/s	
Contact Details	

Their Role	Social Worker
Name/s	
Contact Details	

Their Role	Home care service and names of key people providing care at home
Name/s	
Contact Details	

Their Role	Counsellor
Name/s	
Contact Details	

Their Role	Occupational Therapist
Name/s	
Contact Details	

Their Role	Physiotherapist
Name/s	
Contact Details	

Their Role	Massage Therapist
Name/s	
Contact Details	

Their Role	Rongōa Practitioner
Name/s	
Contact Details	

Their Role	Natural Therapist
Name/s	
Contact Details	

Their Role	Music / Art Therapist
Name/s	
Contact Details	

Their Role	Chaplain / Spiritual Carer
Name/s	
Contact Details	

Their Role	Meal Delivery Service
Name/s	
Contact Details	

Personal notes

Kia hora te marino,
kia whakapapa pounamu te moana,
kia tere te kārohirohi i mua i tōu huarahi

May the calm be widespread,
may the ocean glisten as greenstone,
may the shimmer of light ever dance across your pathway



www.hospice.org.nz

To talk with us at Hospice New Zealand please phone 04 381 0266

Te Kahu Pairuri
o Aotearoa
hospice
New Zealand

