



Navigating the End of Life Journey

A brief overview of the vast support
available to you and your loved ones



HONOHONO TĀTOU KATOA
Creating Compassionate Communities

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CONTENTS

Ko wai tatou - who are we?	Page 1
The Why	Page 2
The River	Page 3
I Want to Know More.....	Page 4
My Whānau Member Needs Support.....	Page 5
Te Hokinga ā Wairua End of Life Service....	Page 6
What questions should you be asking?.....	Page 7
I Need Support.....	Page 8
Needs Assessment & Service Co-ordination...	Page 9
After Death Support.....	Page 10
Legal Stuff.....	Page 11
Kaupapa Māori Support.....	Page 12
Compassionate Communities.....	Page 13
Your personal notes/questions.....	Page 14



Any questions? Send them to info@honohono.net

KO WAI TĀTOU WHO ARE WE?



HONOHONO TĀTOU KATOA Creating Compassionate Communities

At Honohono Tātou Katoa, we understand the value of recognising death as an integral part of life. We're driven by the vision of fostering compassionate and empowered communities and ensuring equity in end-of-life care.

Our approach:

- Re-Indigenise ourselves and our practice
- Create safe spaces for diverse communities
- Have open and honest kōrero/conversations around death and dying
- Enhance mana and knowledge of communities through accessible education, community events, and systematic change
- **Support communities to be able to confidently navigate the journey of “before, during and after death” with dignity and choice.**

“ People and communities overwhelmingly want to know what palliative care really is, how to navigate the system when it’s needed and how to care for the people who matter most to them. They want to know how to help, and to learn how to get help when it’s needed. None of this is rocket science.

It is about two-way sharing of information between partners. ”

Dr. Carol McAllum
Project Lead of Honohono Tātou Katoa

Navigating the system can feel like being whipped through white water rapids, or being guided purposefully down a river - depending on what you know!



I want to know more

My whānau member needs support

I need support as a caregiver/friend/whānau member

Support after death



I WANT TO KNOW MORE

(LET'S BUST A FEW MYTHS!)

What is palliative care?

Mercy Hospice NZ says: "Palliative care is for people who have a life limiting condition; meaning there is no cure for their condition - that is they are living with an advanced life-limiting illness. The primary goal is to provide comfort and dignity for the person living with the illness until they die, maximising the best quality of life for them and those around them"

Does palliative care mean the end?

Not necessarily!!

"A palliative approach to care can be used at any time in your illness, not just when you are at the end of your life. Using palliative care does not mean there is no hope, you have 'given up' or your family doesn't care."

- Palliative Outcomes Initiative (POI).

Is palliative care just for older people?

Palliative care is available to anyone who needs it, regardless of age. Palliative care for children and young people is different to care for adults in that it also helps families make important decisions about their child's care

Where does palliative care happen?

People in their last phase of life spend 95% of their time in community. They and their caregivers and the bereaved, spend 95% of their time either alone, with friends or family, with neighbours or colleagues, with animal companions, maybe with the internet or television. Only 5% is spent with healthcare providers.





MY WHĀNAU MEMBER NEEDS SUPPORT

Accessing services

Hearts and Minds: Over 600 free/low-cost support options at your fingertips. Search for cancer services, mental health support, disability services, and more.

heartsandminds.org.nz

Citizens Advice Bureau: Understand your rights and what you can access regarding health and wellbeing

cab.org.nz

Planning for the future

Advance Care Plans: An advance care plan is a document created by you outlining how you would like to be cared for in the future.

myacp.org.nz

Te Hokinga ā Wairua End of Life Services: Find information to help you create and share a personalised plan of what you want to happen when you die.

endoflife.services.govt.nz

Having conversations

Healthify NZ: If someone close to you has a terminal illness, it's important for you to be there to listen and to provide emotional and practical support.

healthify.nz/palliative-care-talking-about-dying/

End of Life Doulas: doulas can assist you and your whānau in having difficult conversations, doing life reviews, vigil planning, and more.

eldaa.org.nz/find-a-doula



What to Google: "CAB care of older people" "ACP NZ"
"how to talk about dying nz"

TE HOKINGA Ā WAIRUA END OF LIFE SERVICES

Information and tools to help guide people facing the loss of a loved one, or to record your preferences ahead of time to make it easier whānau and friends to understand your wishes.

Someone's died and I need information

- Find information about what to do, and services that might be available to you, following the death of a loved one.

I want to plan and share my wishes and information

- Find information to help you create and share a personalised plan of what you want to happen when you die.

Search for services based on your location:

- someone to talk to
- legal advice
- help organising a funeral
- kaupapa Māori services

endoflife.services.govt.nz



MY WHĀNAU MEMBER NEEDS SUPPORT

What questions should you be asking?

Speaking your mind and asking questions can be intimidating but can help you and those closest to you understand your illness journey.

These 3 sets of questions will help you be more informed, have more choice and control, and be more hopeful and prepared.

Info from Health Canada (2023)

What does it mean to have this serious illness?

Not all serious illnesses are the same. Some can be cured while others can't. A person might have the illness their entire life. And some serious illnesses will get worse over time and shorten the person's life. It is important to know the nature of the illness.

Ask your health care team:

- Is the illness curable?
- Will it get worse over time?
- Will it shorten my life?

What can I expect now and in the future?

Every person's experience is unique. But each serious illness has a general pattern based on the many people who have had it before. Thus, it's possible to learn what the illness looks like in the early, middle and later stages. Having a general sense of this pattern will help you understand where you are at in your illness and what you can expect in each stage.

Ask your health care team:

- Can you explain the big picture and the different stages of the illness?
- Am I currently in the beginning, middle or later stage of my illness?

How can I prepare for what might come next?

Throughout the illness there will be times when you need to make important decisions about what to do next. Combining information about what to expect, where things are now and what is most important to you will help you work with your health care team. Doing this will help you make decisions about your care that are right for you and those closest to you.

Ask your health care team:

- Can you explain what milestones and decision points are ahead in my illness and how we can plan for them?

Ask yourself:

- What's most important to you and those closest to you? Share this information with your health care team.



I NEED SUPPORT

Financial support

Needing financial assistance at this time is common, and there is support out there.

You can try:

Citizens Advice Bureau

www.cab.org.nz

Nga Tangata Microfinance Trust

ngatangatamicrofinance.org.nz

021 268 7348

Work & Income NZ

workandincome.govt.nz

0800 559 009

Counselling support

If you, or someone you know, needs support you can go to your family doctor or:

- **Skylight.org.nz** offer counselling, support, resources and personalised information packs.
- **GriefCentre.org.nz** offer counselling, support groups, brochures, books and articles.
- **[New Zealand Association of Counsellors](http://NewZealandAssociationofCounsellors.org.nz)** (nzac.org.nz) can help you find a counsellor near you to help with grief and loss.
- **[Employee Assistance Programmes](#)** offer free counselling in some workplaces – ask your employer about this.

The power of community

- **Support Crew** | supportcrew.co
 - Support Crew is a FREE online support platform that easily co-ordinates meals, transport or any other help that's needed from family and friends.
- **Sweet Louise** | sweetlouise.org.nz
 - Sweet Louise provides practical and emotional support for New Zealanders living with incurable breast cancer.
- **Kenzie's Gift** | kenziesgift.com
 - Kenzie's Gift supports the mental health of tamariki (children) and mātātahi (young people) affected by serious illness or grief.
- **Cloud Workshop** | cloudworkshop.co.nz
 - Art workshops for bereaved children and those with life-threatening illness in their family
- **Carers NZ** | carers.net.nz
 - Carers NZ acts as the national peak body providing information, advice, learning and support for carers.
- **TimeOut** | timeoutnz.org
 - TimeOut is a New Zealand charity that connects generous holiday home owners willing to donate a stay in their property to people diagnosed with a terminal illness



What to Google: "Meet Up Auckland" - Find events in Auckland to connect with people who share your interests

Needs Assessment and Service Co-ordination (NASC)

NASC are concerned with the long-term support needs of elderly people who have a disability, and the needs of their carers. They aim to assist older people to live at home, safely and independently, for as long as possible.

A Needs Assessment is the first step towards getting the support or services you and your family require if you have a long-term disability.

A needs assessment determines your strengths, needs and goals and identifies the services required to support you to be as independent as possible.

NASC provides services for adults under 65 years who have very high support needs as a result of chronic disease. NASC provides services for people 65 years old and over living in the Central Auckland area as a part of Home and Older People's Health.

A needs assessor will visit you and work through an assessment with you. The assessment identifies tasks that you find difficult and discovers what support others e.g. family/whānau, community support groups, etc., can provide. The assessor will then identify which needs will require support from formal services.

Once a needs assessment has been completed, the service co-ordination team develops a support plan to maximise independence at home. This includes purchasing, managing access to and monitoring usage of, support services.

Contact options

NEEDS ASSESSMENT AND SERVICE CO-ORDINATION

PHONE: 0800 631 1234

RESPIRE CARE

PHONE: (09) 307 4949 ext.27852

SENIORLINE

PHONE: (09) 375 4395 or 0800 725 463

NASC can also help with respite care and Seniorline which operates New Zealand-wide for older adults and their families/whānau.

Support services available:

a) Domestic Help - housework, laundry, shopping.

Note a Community Services Card is required for domestic help.

b) Personal Cares - showers/bathing, dressing/undressing, getting up and putting to bed.

c) Social Support - befriending visitors, craft and activity groups.

d) Caregiver Support - relief care, daycare, dementia daycare, support groups.

e) Provision of Information - regarding care in the community, information on disability support groups, e.g. Stroke/Arthritis Foundations, etc.



What to Google: "NASC NZ"

Visit: nznasca.co.nz

AFTER DEATH

Grief support

Skylight: Supporting children, young people, and their whānau to navigate through tough times by building resilient individuals and families

Skylight.org.nz – freephone: 0800 299 100

1737: When someone texts or calls 1737 a trained counsellor will work with the person to develop a care plan. This takes on average between 10 – 20 minutes and could include referral to another service, additional counselling or providing information and support.
1737.org.nz – freephone or freetext 1737

Lifeline: Lifeline Aotearoa is a free mental health support and counselling service. They're there to help you 24/7.

Lifeline.org.nz – freephone: 0800 543 354 freetext: help (4357)

Samaritans: Anonymous & non-religious, Samaritans operates a 24/7 crisis help line. Their phones are operated by volunteers from the community for the community.

Samaritans.org.nz – freephone: 0800 726 666

Funeral options

Funerals are highly individual. The best thing you can do is “get an estimate of the costs” and make sure you have conversations about what you need from the funeral director to get the funeral that best suits your needs. There is a lot you can do yourself if you would like to – check out [diyfuneral.co.nz](https://www.diyfuneral.co.nz) for comprehensive information and support.

My Trove

You can notify multiple organisations at the same time using myTrove- it's is an online service where you can notify multiple organisations about someone's death. It's free to use. Visit mytrove.co.nz



What to Google: “What needs to be done after a family member dies? CAB” to find a comprehensive list of tasks on the Citizens Advice Bureau website.

What legal stuff do we need to think about?

Creating a will

You can get one drafted by someone with experience, such as a lawyer or trustee company. A will must also be signed and witnessed. If the proper procedures are not followed, a will may not be valid. Wills don't have to be pricey. Some lawyers will even write one for free, so there's no harm asking around.

Some options:

- **publictrust.co.nz** [price varies]
- **gatheredhere.com/nz/make-a-will-online** [basic is free with option to pay for add-ons]
- **nzwillkit.com** [from \$30]

POA AND EPA

A power of attorney is a legal document that allows someone to make decisions and sign documents for you, if you become unable physically or mentally unable to do this yourself. You need to think carefully about who you give this power to.

The most common type of power of attorney is an enduring power of attorney (EPA). You can either have an EPA for personal care and welfare or property.

It will take effect if you become sick or mentally incapable.

More info at: **publictrust.co.nz/products-and-services/enduring-power-of-attorney**

Confirming and registering the death

When someone dies, the death and the cause of death have to be confirmed by a doctor or nurse, or sometimes by the coroner, before the body can be buried or cremated.

In most cases this will be confirmed by a doctor or nurse, who'll issue a "Certificate of Cause of Death". As well as this official confirmation of death, there are other documents the funeral director or relatives will need to complete or obtain from others - for example, special approval forms if the body is to be cremated.

After the deceased's body has been buried or cremated, the death must be officially registered with Births, Deaths and Marriages at the Department of Internal Affairs, who'll then issue an official "Death Certificate".

More info at: **communitylaw.org.nz**



What to Google: "What to organise before you die - Death and bereavement"

Kaupapa Māori support

TE IPU ARONUI

Te Ipu Aronui is a site to support Māori whānau (families) to provide care to adults and kaumātua (older people) at end of life, as well as take care of whānau at the same time. Go to **teipuaronui.co.nz** to explore

TE RANGIKAHUPAPA FUNERAL SERVICES

Kaupapa Māori funeral services, creating affordable and bespoke packages according to whānau need: **terangikahupapa.co.nz**

PUĀWAITANGA

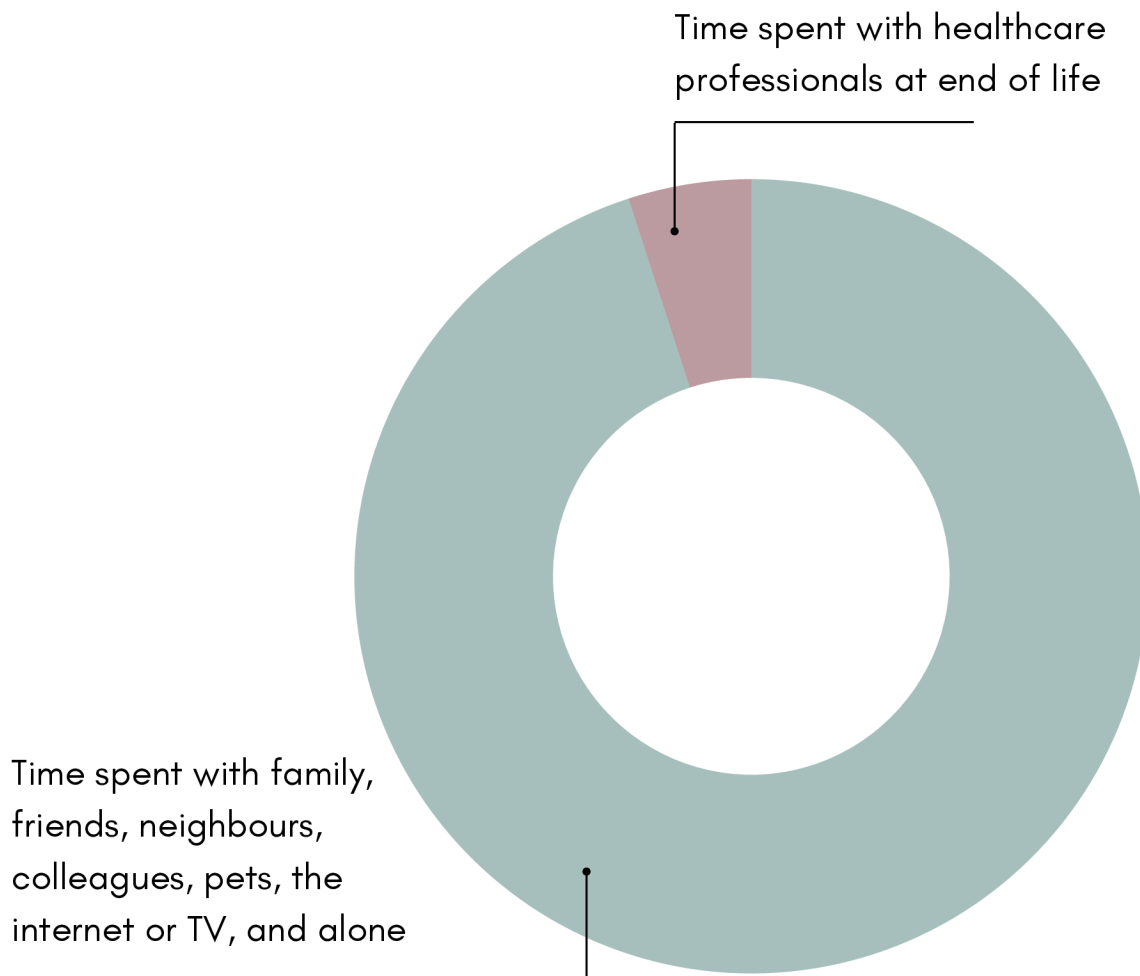
Puāwaitanga is a phone and web-based service to support people of Aotearoa New Zealand to improve their emotional wellbeing - go to **whakarongorau.nz/puawaitanga** to check eligibility.

TE KOTUKU KI TE RANGI TRUST

These are intensive, individual and comprehensive flexible 'packages of care' services for tangata whaiora and their families based on the principle of recovery. Go to **tekotuku.co.nz**



WHY THIS MATTERS



What are compassionate communities?

IT CAN LOOK LIKE: Communities of people who are passionate and committed to improve the experiences of those living with a serious illness, caregiving, dying and grieving.

CARE FOR ALL: Compassionate communities take an active role in caring for people affected by these experiences. It focuses on quality of life and gives everyone a chance to live their lives fully until the end.

WHO CAN DO IT: Much of the care needed for people at the end of life doesn't have to be performed by professionals. Some important things anyone in the community can do:

- Getting dinner prepared
- Helping with transport
- Taking the rubbish out

Some things to remember

YOU'RE NOT
ALONE

Let the main takeaway from this be that at no point are you alone on this journey. Support is there every step of the way if you need it.

YOU'RE
DOING THE
BEST YOU
CAN

There is no right or perfect way to do things. Be kind, be patient, and be gentle with yourself.

REACH OUT
ANY TIME

You don't have to wait until things are "bad enough" to ask for help. Reach out at any time to your loved ones, your community, your GP, or any helpline listed in this guide.



WAIHO I TE TOIPOTO, KAUA I TE TOIROA
LET US KEEP CLOSE TOGETHER, NOT WIDE APART

