Nanipā’s Choice

MANA MOTUHAKE IN LIFE AND DEATH

Karakia mō te Pae Tukutuku o te Mate Whakaahuru

Tau mai rā ko te kōrero o tuaukiuki hei ārahi
Tau mai rā ko te manaakitanga o ngā mātua tūpuna hei tiaki
Tau mai rā ko te aroha o te wāhi ngaro hei whakamāmā
i tā mātou haerenga i tēnei ara tapu o te mate whakaahuru.

Kia ū tonu mātou ki te tika
Kia ū tonu mātou ki te pono
Kia ū tonu mātou ki te aroha
Mō te hunga e takatū ana
Mō te hunga e manawa kiore haere ana
Mō ngā whānau e tangi ana
Mō ngā ringa atawhai e tautoko ana.

Tukua mai te āio o Ranginui e tū iho nei
Tukua mai te aroha o Papatūānuku e takoto nei
Tukua mai te hau maiangi o Tāwhirimātea
Tukua mai te whakapapa pounamu o te moana o Tangaroa
Tukua mai te pono o ngākau
Hei ārahi i ā mātou mahi katoa.

Haumi ē, hui ē,
Tāiki ē!

May the ancient words of wisdom guide us
May the tenderness of our ancestors protect us
May the love of the unseen realm care for us
and lighten our steps on this sacred path of assisted dying.

We remain steadfast in what is right
We remain committed to what is true
We remain anchored in love
For those preparing to journey beyond the veil
For the grieving whānau who remain behind
and for the caring hands that provide support.

Bestow upon us the tranquility of Ranginui
Bestow upon us the love of Papatūānuku
Bestow upon us the gentle breezes of Tāwhirimātea,
Bestow upon us the glistening of the seas of Tangaroa
Bestow upon us a sincerity of heart
To guide all that we do.

Let it be bound, let it be joined,
It is so!

WRITTEN BY TE HURINUI KARAKA-CLARKE

Acknowledgements

We are grateful to whānau who took part in the Waerea study on assisted dying as their stories and experiences helped to inform *Nanipā's Choice* and *Walking Sunny Home*. Māori hold diverse and sometimes conflicting views on assisted dying and palliative care. The stories presented here do not seek to resolve those differences or suggest one singular or contemporary end of life pathway. Instead, the stories make space for mana motuhake (autonomy, independence), whānau (family) decision-making and for tino rangatiratanga (self-determination) while prioritising tikanga (customs), compassionate care and cultural and spiritual safety.

We honour the whānau, kaumātua, kuia, tohunga, matakite, kaiāwhina and kai rongoā who use their ancient tikanga and contemporary healing practices to provide care to people at the end of life. Their contributions echo that caring for the dying is relational, cyclical and grounded in mātauranga Māori. We also acknowledge the clinicians, allied health professionals and funeral directors who care for terminally ill people and grieving whānau.

We honour the sacredness of whānau during each phase on the *Kaitiakitanga Assisted Dying Pathway*. May these stories protect everyone's mana and uphold wairua at the end of life.

WHAKATAUKĪ

Kia tau te rangimarie
Kia hāngai te ara ki te mārama
Kia toitū te mana o te tangata me tōna whānau.

May peace settle and be ever present
May the journey be guided by the rhythms of the moon
May the dignity, authority, and integrity of the person
and their whānau endure.

Ae, I can hear you. I'm ready, are you?


I'm sorry, Hemi, your condition has got a lot worse. I think it is best you see the palliative care team. They're trained in caring for people with terminal illnesses.
What's palliative care?
Can we get a second opinion?

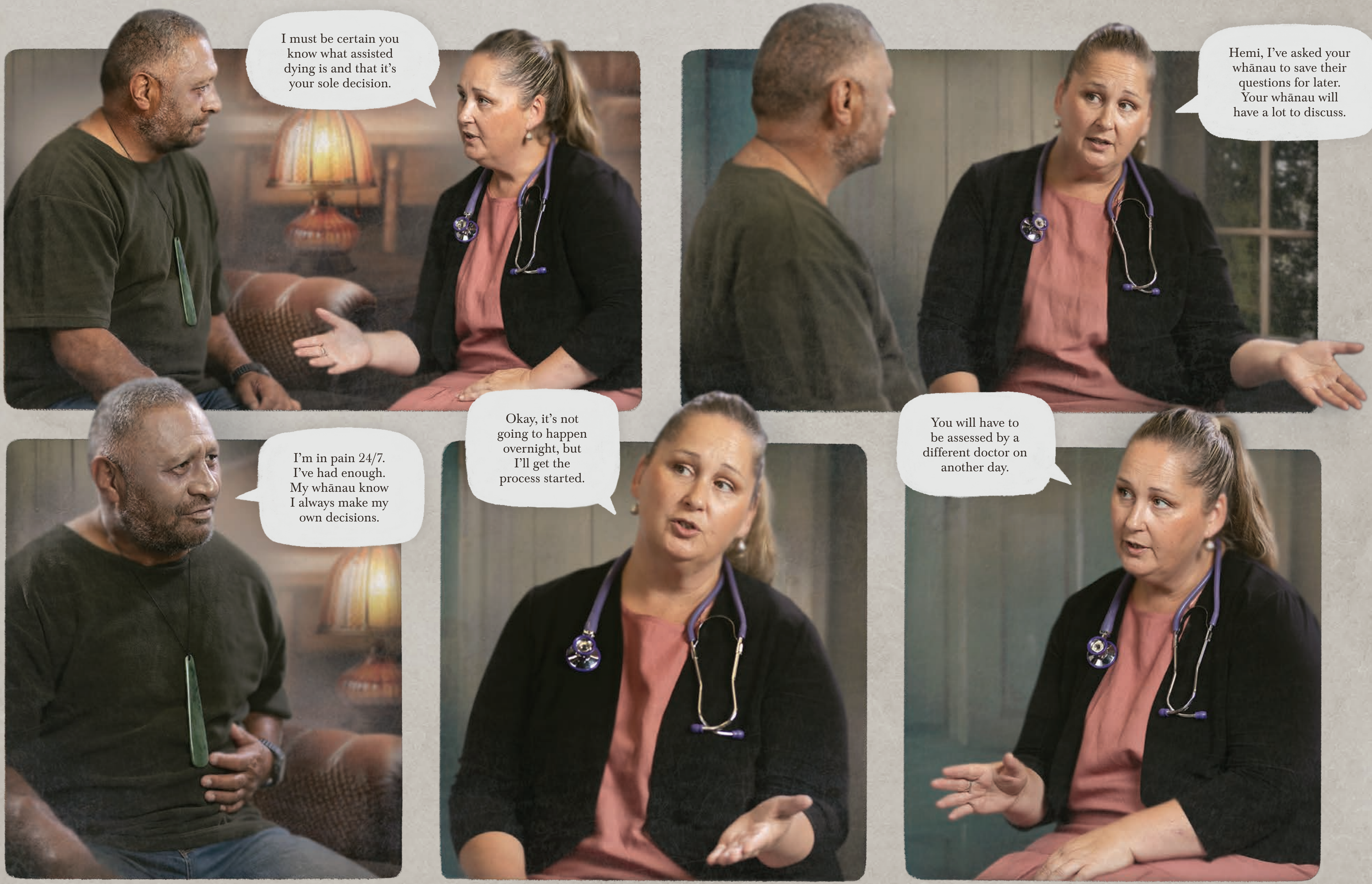

I wish I could tell Hemi about assisted dying, but legally I can't. He has to raise it with me first.
I don't want to die in pain like my wife did.


You seem sad, Aroha?
It’s not just the tohorā. I’m upset about you, Nanipā.
Don’t cry moko. Our tuākana know when their time is coming.
And so do I.


This should help ease the pain, Hemi.
Just knock me on the head Mere – same as when the cows get sick.


Nanipā, did you mean it? Do you really want to die?
The pain's getting the better of me.
I don't want you to go, but...
Doctors can give medicine to people who are terminally ill to end their lives, Nanipā. It's called 'assisted dying'.
You have to ask a health professional for it though, or call the 0800 number.
Ae, I remember voting for euthanasia a few years ago.


As an attending medical practitioner for the Assisted Dying Service, I must emphasise that this must be your decision, Hemi.
Damn, I can't believe what I'm hearing.


I must be certain you know what assisted dying is and that it's your sole decision.
Hemi, I've asked your whānau to save their questions for later. Your whānau will have a lot to discuss.
I'm in pain 24/7. I've had enough. My whānau know I always make my own decisions.
Okay, it's not going to happen overnight, but I'll get the process started.
You will have to be assessed by a different doctor on another day.


Doc, can't you just give Pāpā stronger painkillers?
C'mon, settle down, boy.


There's nothing more the docs can do. I'm having it and don't go telling everyone. It's my business.
It's what Pāpā wants, bro. Let's support him.
Whatever you need, Hemi. We're here for you.


E te Atua, take good care of my whānau. I know they'll miss me, especially my moko girl, Aroha.
BIBLE


Thank you, doctor. The whānau are happy he maintained his mana motuhake.


Is it my fault Nanipā's not here? I was the one who told him about assisted dying.
Your Nanipā knew it was his time Aroha, just like the tohorā did. You helped him because you loved him and you listened deeply.

THE END

Afterword

E te whenua, e ngā maunga whakahī, e ngā awa whakatere tangata, tēnei mātou e mihi ana. We deeply thank all the participants who took part in the Waerea study. Thank you for entrusting us with your stories as these carry wairua and hope. Your profound courage, generosity and deeply moving experiences have informed the production of two fictional pūrākau (stories); *Nanipā's Choice*, a pūrākau about assisted dying and *Walking Sunny Home*, a pūrākau about palliative care.

These pūrākau were informed by participants' experiences. Information about the Waerea study (Māori assisted dying researh project) can be found on the Pou Kāpura website: www.poukāpura.co.nz or www.poukaapura.co.nz.

Information about palliative care for Māori can be found at www.teipuaronui.co.nz.

We are grateful to the Te Ārai Kāhui for upholding tikanga throughout the project ensuring cultural, spiritual, and ethical safety was observed. Thank you to the Waerea Study Advisory Group for their invaluable expertise and knowledge in the fields of palliative care and assisted dying.

We acknowledge the Health Research Council of New Zealand for funding the Waerea study (2023 – 2026).

BACKGROUND

Nanipā's choice

He aha te mea nui o te ao?
He tāngata, he tāngata, he tāngata.

What is the most important thing?
It is people, it is people, it is people.

Nanipā's Choice was written by Dr Tess Moeke-Maxwell to highlight Māori whānau experiences of assisted dying in Aotearoa, New Zealand.

Dr Tatiana Tavares brought the book to life with her beautiful illustrations and Dr Lisa Williams provided editing support and guidance.

Our sincere thanks goes to Nette Scurr for her manaaki (care) and support. Our gratitude goes to whānau, friends, colleagues, and members of Te Ārai Kāhui who volunteered to be actors in *Nanipā's Choice*. Each person took part in a photographic session that lasted up to two days:

Nanipā – Te Hirinui Karaka-Clarke
(Te Arawa, Ngāi Tahu)

Aroha – Ebony Komene
(Ngāpuhi, Ngāti Pikiao, Ngāti Whakaue, Tapuika)

Moana – Lexy Ngawaka
(Waikato, Ngāti Rongomaiwahine, Ngāti Rakaipaaka)

Piripi – Philip Raukawa (Tūwharetoa)

Nanipā's sister – Emma Raukawa (Tūwharetoa)

Koro – Aaron Ngawaka (Ngatiwai, Ngāti Rehua)

Attending Medical Practitioner (AMP) –
Racheal Raukawa (Ngāi Tai ki Tāmaki, Ngāti Porou)

General Practitioner – Tess Moeke-Maxwell
(Ngāi Tai ki Tāmaki, Ngāti Porou).

Introduction

Nanipā's Choice is a fictional pūrākau (story) located on the east coast in the upper North Island of Aotearoa. Although Nanipā's whānau are fictional characters there are many elements of this story that resemble the experiences of whānau who took part in the Waerea study. The main aim of the pūrākau is to raise awareness about the End of Life Choice Act (2019), including how to access and use the Assisted Dying Service. Assisted dying is "a new way of dying" as one kaumātua we interviewed explained. Being new, assisted dying may seem "different" or "strange" to whānau. Whānau often find it difficult to find information about assisted dying, a term which has a different meaning to the more familiar word "euthanasia."

The person who has a terminal illness will need to consider all the options available to them, including assisted dying. For example, they will need to choose who to tell and how much information they want them to know. Many whānau told us that keeping assisted dying private was especially important as they wanted to protect the seriously ill person from judgement from non-supportive whānau, friends and health professionals. Only close whānau or friends were invited to walk alongside the person and attend their assisted dying assessments and procedure.

We hope *Nanipā's Choice* will encourage whānau to engage in conversations about palliative care and assisted dying as there are many choices the person who is wanting an assisted death has to make.

The person who is terminally ill will need to choose the date they will have the assisted dying procedure. Sometimes the dying date clashes with a special occasion such as a son or daughter's birthday or another important event. Therefore, the person may need support to choose a dying date. They will also be asked to choose if they would like to take the assisted dying medication themselves or have the assisted dying doctor (attending medical practitioner or nurse practitioner) administer the medication.

We believe whānau who discuss assisted dying together as a whānau will be better equipped to care for each other. Whānau who are informed and who understand each other's preferences and needs will feel more confident planning and preparing for what lies ahead. It is important to have these discussions as an assisted death is not something that everyone may be able to support. People can discuss how involved they want to be. For example, someone may feel comfortable supporting a parent or a sibling to have an assisted dying assessment; however, they may not wish to be present when that person has the procedure to end their life. The most important thing is that everyone is taken care of, and everyone is fully aware of their choices.

Cycle of Life

In the opening scene, we draw attention to Nanipā's connection to te taiao (the natural environment) and his connection with his tuākana (older sibling), the tohorā (whale) and the cycle of life. Nanipā has a special relationship with the tohorā who has been visiting his coastal home for several weeks. Nanipā senses changes in tohorā and he also notices changes happening in his own tinana (body) and wairua (spirit). As Nanipā's death draws near, he senses the life cycle of tohorā is also changing. Their transition has begun.

End of Life Choice Act (EoLC) 2019

Nanipā visits his doctor because his tiredness and physical symptoms have become much worse. He is supported by his son Piripi and his daughter Moana. His general practitioner (GP) has the challenging task of telling Nanipā that his clinical tests are conclusive – there is no cure for his illness. His doctor refers him to palliative care (care of body, spirit, emotions and also care of his bereaved whānau). The GP's thought bubble alerts the reader to Safeguard 10 in the EoLC Act (2019) which legally prevents health professionals from raising assisted dying with a patient unless they raise the subject first. Nanipā leaves the doctor's office unaware that he is entitled to ask for a referral to the Assisted Dying Service.

The End of Life Choice Act came into effect on 7 November 2019. Assisted dying involves a person who is experiencing unbearable suffering from a terminal illness, with less than six months to live, taking or being given medication to end their life. There are safeguards in the EoLC Act and strict eligibility criteria apply for people who want to use the Assisted Dying Service. Not everyone with a terminal illness will be eligible. For example, people cannot have an assisted death based on disability, advanced age or mental illness, unless they also have a terminal condition and meet the assisted dying criteria.

Introducing Nanipā to assisted dying

When Aroha, Nanipā's mokopuna (grandchild), listens to her grandfather telling his sister, "Mere, just knock me on the head – same as when the cows get sick," she uses the internet to see what help is available to assist him. Aroha advises her grandfather that he has to contact the Assisted Dying Service to make enquiries about assisted dying. Aroha cautions Nanipā that health professionals are not allowed to raise the subject with a person. It is often difficult for whānau to find information on assisted dying, and they do not know who to talk to about it. Whānau believe a doctor will tell them about assisted dying at the time they are told they have a terminal diagnosis but currently, this is not the case:

EoLC Act (2019), Safeguard 10: A Health Care Professional providing any health service to a person must not:

- Initiate any discussion with the person that, in substance, is about assisted dying; or
- Make any suggestion that, in substance, is a suggestion that the person exercise the option of assisted dying.

Supporting someone who wants an assisted death

Whānau find out about assisted dying in a variety of ways; some people may seek information from their GP, or they may ask any person in their healthcare team. They may also approach someone in their whānau to help them. Whānau would prefer that doctors tell them about assisted dying when they discuss the options available to them at the end of life, including palliative care.

Whānau experience deep mamae (emotional pain) after learning that someone they love has a terminal diagnosis. If that person makes it known that they wish to hasten their death by having an assisted death their whānau are likely to support them; however, at the same time they may also feel confused about assisted dying. Feeling confused or having mixed emotions about assisted dying does not prevent whānau from wanting to be involved. Most whānau will support the person with a terminal illness and walk alongside them even if assisted dying is not something they personally agree with. Indeed, not everyone will choose to be actively involved, or attend the assisted dying procedure, particularly if they have strong cultural or spiritual views that prevent them from supporting the person's decision.

Conscientious objectors

Under the EoLC Act (2019) conscientious objectors (people who do not agree with assisted dying) have a legal obligation under the EoLC Act (2009) to inform a person enquiring about assisted dying of their objection. Importantly, they are also obligated to tell the person where they can find information about the Assisted Dying Service and connect them with a health practitioner who can support them with the process.

Having an assisted dying assessment

Dr Sophie is the Attending Medical Practitioner (AMP) for Nanipā's first assisted dying assessment. She has an important job to do. If Dr Sophie suspected coercion or pressure from whānau or anyone else, the assessment process would be stopped. Dr Sophie tells Nanipā that legally, he has to make the choice for assisted dying by himself. She has the responsibility to check that Nanipā is not being pressured by anyone to have an assisted death. It important for whānau to understand that the AMP is certain that the person is choosing an assisted death on their own terms.

Section 24 of the EoLC Act (2019) states that if a healthcare professional suspects on reasonable grounds that a person who has expressed the wish to receive assisted dying is not expressing their wish free from pressure from any other person, they must take no further action to assist the person and they will record and notify the assisted dying registrar at Te Whatu Ora.

Dr Sophie reminds Nanipā that he can change his mind about having an assisted death at any time. She discusses his end of life care options and wishes, including the role of the palliative care services, such as hospice. She makes it clear to Nanipā's whānau that they can ask questions after she has conducted her assessment. She encourages Nanipā to discuss his wish to have an assisted death with his whānau however, he does not have to tell his whānau if he does not want to; it is his choice.

Dr Sophie informs Nanipā that she will talk to other health professionals about his illness and his application for an assisted death. With Nanipā's permission she will also talk to his whānau if that is his wish. Dr Sophie explains that Nanipā will have a second assessment by another doctor who has the role of Independent Medical Practitioner (IMP). The role of the IMP is to make ensure that Dr Sophie's decision is correct and in line with the eligibility criteria for assisted death. Dr Sophie also informs Nanipā that sometimes it is necessary for a third assessment to take place by a psychiatrist (a doctor who is an expert in mental health). Feeling certain there is no sign of coercion or pressure from others Dr Sophie signs the assisted dying form. Nanipā has verbally consented that he wants to go ahead with an assisted death. Dr Sophie then registers his request with the Assisted Dying Service.

Disclaimer

The volunteer actors and actresses who have generously contributed their time and presence to this publication hold diverse personal views regarding assisted dying. Participation in this project does not indicate endorsement or opposition to assisted dying under the End of Life Choice Act (2019). Rather, their involvement reflects a shared commitment to kaupapa Māori research that seeks to support whānau with accurate information, cultural safety, and compassionate understanding as they navigate complex decisions at the end of life.

This book is intended to foster informed discussion, uphold mana motuhake, and strengthen the ability of Māori adults who have an incurable terminal illness, to make choices grounded in their own values, beliefs, and tikanga. It is also intended to support whānau to navigate the *Kaitiakitanga Assisted Dying Pathway* alongside family members who have chosen to have an assisted death.

We honour the integrity, courage, and generosity of all contributors.

Pōuritanga (sadness) – loss and grief

Assisted dying can add another layer of mamae (emotional pain) for whānau who are already feeling pōuri (sad, mournful). Nanipā's whānau expressed a range of emotions during his assessment with Dr Sophie. Naturally, everyone in his whānau felt mamae because they knew that Nanipā was dying. Nanipā's whānau are trying to manage their grief, in their own ways, and in their own time, using their own resources. Hearing about Nanipā's wish for an assisted death has given them something else to think about and process.

Piripi expressed his emotions about his pāpā's choice to have an assisted death – he shows his hurt and anger. Piripi does not understand why Nanipā cannot simply have more pain medication to reduce his pain and symptoms. Piripi's response is normal. Whānau can feel mamae, pōuri, upset, angry, confused, and unsure when someone expresses their wish for an assisted death. However, whānau can also feel proud of their whanaunga (relative) for holding on to their mana motuhake (autonomy and independence) and decision making until their last breath.

Nanipā's whānau understood why he chose to have an assisted death; he did not want to die in pain like his wife did. He also wanted to maintain his mana (power, control, prestige). To die in a dignified way was important for him.

Nanipā also wanted to reduce the burden of care on his whānau. Although some people may choose an assisted death to reduce the responsibility placed on their whānau who support them, whānau feel strongly this is not a good reason to have an assisted death. Whānau have commented that the person who wants an assisted death is not a burden on them and it is "privilege" to care for them at the end of their life.

Grieving before, during and after someone dies

At the beach, Aroha expresses her sadness at Nanipā's news – he has a terminal diagnosis. She also grieves for the tohorā. However, when Aroha hears her grandfather's painful cry for help; her love for him outweighs her own thoughts to keep him longer. Nanipā has been a farmer, and a shearer of sheep and he believes farm animals who are suffering should be euthanased. Aroha heard Nanipā's cry for help because she listened to him deeply; she responded by finding information about assisted dying.

The process of mourning is something that happens naturally as whānau walk alongside someone during their final months, weeks, days, and hours of life. Whānau mourn the little and big losses as an illness progresses; there is the loss of not being able to work, not being able to carry a mokopuna (grandchild) on the hip anymore, loss of enjoyment of food, loss of not being able to garden or carry on with sport, loss of bodily functions and adjusting to changes in one's oranga (well-being). There are also huge losses as relationships change.

Bereavement can be particularly challenging for whānau when they are not informed someone they love and care about is having an assisted death. People can feel very excluded when this happens. It can also be incredibly challenging for whānau who are not given much information about the assisted dying process and procedure. Whānau need to understand the assisted dying process and what is happening, especially on the day of the procedure. It is important that whānau have the opportunity to ask questions and to express any concerns they have about assisted dying at every stage of the process.

After Nanipā died, Aroha struggled with her grief; she felt guilty. She asked Mere if it was her fault Nanipā died because she was the one who found the information about assisted dying and gave it to him. Mere reassures her that she listened deeply to her grandfather, and she helped him to maintain his mana motuhake because he got his wish to have an assisted death. This helped Aroha to make meaning of what happened, and it eased her sense of guilt; she was able to forgive herself and this helped soften her grief.

Whānau often feel they are in some way to blame for their loved person having an assisted death because they supported them with the planning and preparation. These feelings are normal. Whānau find their own ways of forgiving themselves and healing such as walking in the bush, swimming in the ocean, talking to whānau and friends or receiving healing from kai rongoā (healers) and tohunga (experts) in wairua (spiritual) healing. Anything that eases the mamae is helpful. However, some whānau may want to keep their grief to themselves as they may not want people knowing their loved person had an assisted death. They honour the mana of the person who died by upholding their right to privacy.

Te Oro Ngākau Nui Mind Level Tool

We have developed a discussion tool to help whānau consider their views, feelings, and beliefs about assisted dying. Understanding how each person thinks and feels about assisted dying and what their preferred involvement is (helping their whanaunga) can help whānau move through this together. The Te Oro Ngākau Nui tool can be found on the Pou Kāpura website.

It is important that whānau feel comfortable walking alongside and supporting their whanaunga (relative). It is important that they understand the assisted dying process from start to finish, particularly if they are going to be present on the dying day. Whānau can use the Te Oro Ngākau tool individually (each person can record their own thoughts and feelings) or the tool can also be used in a whānau hui to prompt discussion. It can help whānau plan and prepare for assisted death as knowing what people need to keep safe can help reduce mamae (emotional pain). Being prepared helps people navigate the road ahead.

If assisted dying is not something people feel comfortable with, they can discuss their thoughts and feelings with whānau, trusted friends, kaumātua, cultural and spiritual healers, counsellors as well as leaders in their community.

How to access the Assisted Dying Service

Nanipā's Choice has been designed to share information about a contemporary Māori whānau experience of assisted dying. The aim is to support Māori individuals who have a terminal illness and their whānau to make informed decisions about palliative care and assisted dying. This book does not provide advice about assisted dying or the Assisted Dying Service.

Understanding the terms

Euthanasia

Euthanasia refers to administering medication by a medical practitioner with the intention of ending the life of a person with a terminal illness.

Assisted dying

Assisted dying refers to a medical practitioner prescribing or supplying medication with the intention of enabling a person to end their own life.

Assisted dying criteria

During Nanipā’s assisted dying assessment Dr Sophie needs to be certain that he meets all the legal requirements to qualify for an assisted death. Individuals who have a terminal diagnosis (that is an incurable illness that will end their life within six months) are required by law to meet specific criteria to have an assisted death. Assisted dying eligibility criteria is determined on a case-by-case basis. Each person’s individual circumstances including the severity of their illness and the experiences they are having will be considered. The following criteria must be met:

- Aged 18 years or over.
- A citizen or permanent resident of New Zealand.
- Suffering from a terminal illness that is likely to end their life within six months.
- In an advanced state of irreversible decline in physical capability.
- Experiencing unbearable suffering unable to be relieved in a tolerable manner.
- Competent to make an informed decision about assisted dying.

Assisted dying day - Some considerations

People who have chosen to have an assisted death (and have met the criteria), may worry that they will lapse into unconsciousness (not be awake) and therefore be unable to consent to an assisted death on the dying day. The Attending Medical Practitioner is required to ask the person for their consent (that is 'yes') prior to administering the assisted dying medication. The AMP (doctor) needs to be sure that the person is still in agreement, and they want to go ahead with the assisted death. Whānau are not allowed to be a proxy (consent on behalf of the dying person) if they are unable to verbally consent to having an assisted death on the dying day. However, the person can give assent (physically give a sign they still agree – nod of head, for example).

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If you require information about assisted dying or you wish to access an assisted dying clinical advisor please contact:

Te Whatu Ora
Health NZ's Assisted Dying Service
PHONE: 0800 223 852 (24-48-hour call-back service)
EMAIL: AssistedDying@tewhatuora.govt.nz

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