

# Walking Sunny Home

A WHĀNAU STORY ABOUT PALLIATIVE CARE

# 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 mārāma  
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.*



Kia Ora, my name is Mana. My wife Sunny and I took over my parents' place when they passed away a few years ago.

Our kids, Iraia, Maia and Kimi, love it here. Plenty of freedom. I'm a mechanic and I work from home. Sunny worked for a small goods firm in the city. She used to say, "We're living the dream, Mana."

But everything changed last Christmas.

Sunny and Iraia were riding their horses to get watercress before Christmas. Sunny's horse got a fright and dumped her. She got up, gave her back a quick rub, then jumped back on her horse.

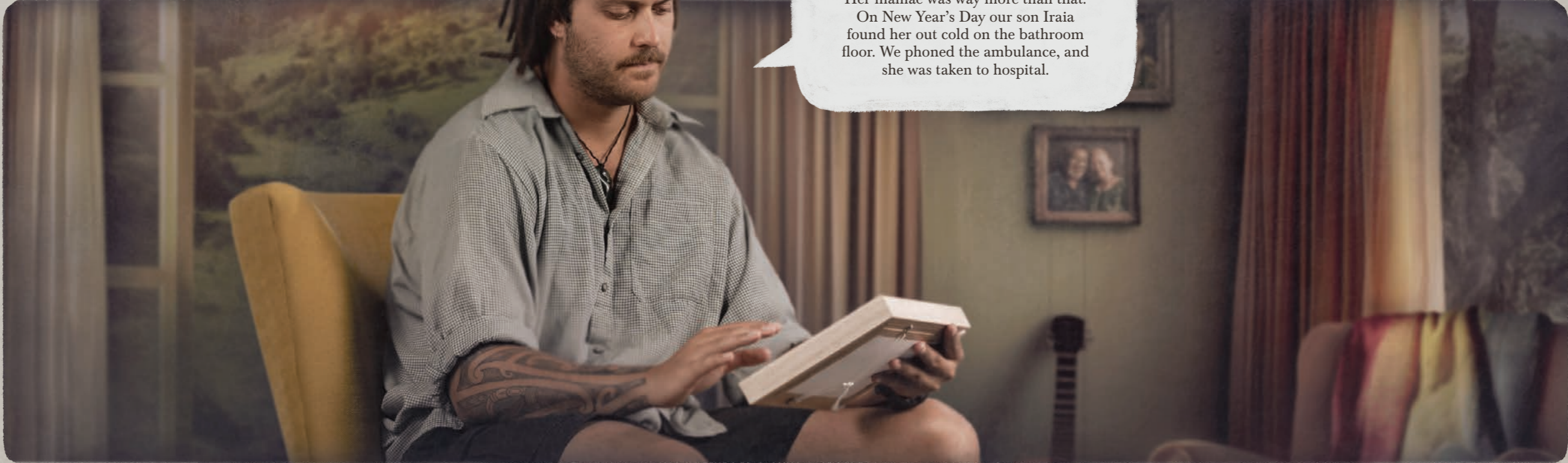


That's my wife; staunch as.




Sunny wasn't well over Christmas. She reckoned it was from the fall because her back was so sore.





Her mamae was way more than that.  
On New Year's Day our son Iraia  
found her out cold on the bathroom  
floor. We phoned the ambulance, and  
she was taken to hospital.

A woman with long dark hair is lying in a hospital bed, looking towards her son. She is wearing a white and grey striped hospital gown. Her son, a young man with dark curly hair, is sitting on a stool to the left of the bed, holding her hand. He is wearing a black t-shirt and denim shorts. A man with long dreadlocks, wearing a blue and white plaid shirt, is sitting on the right side of the bed, looking towards the woman. The hospital bed has white sheets with 'HOSPITAL' printed on them. The background consists of patterned curtains and a wall-mounted light fixture.

Mum, what's wrong with you?

I'm okay, son. Just a bit bruised from the fall, that's all. Pāpā will take me home soon.

Hey 'Dr' Sunny, you're probably right, but let's see what the real doctors have to say.



No! I fell off my horse and hurt my back.

Sunny, your results tell us that you have been sick for some time.

We're really sorry. There's nothing more we can do.


We can refer you to palliative care. The team will help you with pain management and any other symptoms you've got.






Sunny's mum and dad came to help out. We all took care of her. She hated all the fuss, Rongoā kept her comfortable for a long time.

The hardest part for Sunny was telling our whānau she was dying. She asked me to do it. She knew her mum and dad would keep an eye on our kids, but it was Iraia she was really worried about.




Iraia, your Māmā and me –  
all the whānau are worried  
about you. We know life  
wasn't meant to be like this.


There's no shame in telling  
us how you're feeling moko.  
If you're upset just let it out.  
Men cry too.




Iraia, don't be an egg, just talk to us.




Every day I watch you getting sicker. Why can't they fix you? I hate it that you're going to die.



I don't want to leave you, son. My wairua will always be with you. Just think of me and I will be right next to you.



Me and koro will be with you, moko. And your Pāpā and sisters.



Let's have a karakia to get through this.



We met up with the hospice team.  
They came to our home to visit  
Sunny. The hospice nurse and the  
kaiwhakahaere were awesome.







Soon after that,  
Sunny let us know  
she was leaving.





Mana, last night I went down to the beach with Nan. We collected kina.

She's here now.

That's cool, babe.



It won't be too long now. She's letting us know our tūpuna have come to take her.




I love you, Sunny.  
The kids love you.  
We are going to be okay.  
You can go now, babe.

It's been a great  
ride Mana.  
See you fullas on  
the other side.





After Sunny's death, there was one thing that really helped our whānau heal. That was remembering her at Matariki.



Iraia, pour your heart  
out. Maia, Kimi, let  
your tears flow.

Call out your Māmā's name  
loud and strong and look for the  
brightest star in the sky.  
You three were her brightest stars.

THE END

# Afterword

E te whenua, e ngā maunga whakahī, e ngā awa whakaterere 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 research project) can be found on the Pou Kāpura website: [www.poukapura.co.nz](http://www.poukapura.co.nz) or [www.poukaapura.co.nz](http://www.poukaapura.co.nz).

Information about palliative care for Māori can be found at [www.teipuaronui.co.nz](http://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

# Walking Sunny Home

He waka eke noa

*A canoe which we are all in together*

*Walking Sunny Home* was written by Tess Moeke-Maxwell to highlight Māori whānau experiences of supporting someone who is seriously unwell who requires palliative care support. 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 also goes to whānau, friends, colleagues, and members of Te Ārai Kāhui who volunteered to be actors in *Walking Sunny Home*. Each person took part in a photographic session that lasted up to two days:

**Mana** – Travarn Rua-Chase  
(Te Āti Awa, Ngai Tahu)

**Sunny** – Alexandra Ritai  
(Ngāi Te Rangi, Ngāti te Ranginui, Te Ati Awa)

**Son Iraia** (17) – Rongomai Angell  
(Te Aupōuri, Ngā Puhi, Ngāti Whātua, Ngāti Ranginui)

**Daughter Kimi** (15) – Lyric Angell  
(Te Aupōuri, Ngā Puhi, Ngāti Whātua, Ngāti Ranginui)

**Daughter Maia** (13) – Te Arai Angell  
(Te Aupōuri, Ngā Puhi, Ngāti Whātua, Ngāti Ranginui)

**Koro** – Andy Peters (Ngā Puhi)

**Nani** – Shirley Peters (Ngāti Porou)

**Hospice Nurse** – Angela Angell  
(Te Aupōuri, Ngā Puhi, Ngāti Whātua)

**Female doctor** – Gemma Aburn

**Male Doctor** – Dylan Minifie.

# Introduction

*Walking Sunny Home* is a fictional pūrākau (story) located in the central North Island of Aotearoa New Zealand. Although Sunny and her whānau are fictional characters, there are many elements that resemble whānau Tess Moeke-Maxwell has interviewed in her end-of-life research. The main aim of this pūrākau is to raise awareness about palliative care because many whānau have not heard the term ‘palliative care’ before.

## **Palliative care definition**

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life for seriously ill people and their families’ facing problems associated with a life-threatening illness. It focuses on preventing and relieving suffering through early identification, assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual. Palliative care provides support to help people live as actively as possible until death and offers support to families during the illness and in their own bereavement.

## **WHĀNAU PROVIDE PALLIATIVE CARE**

Palliative care means holistic support and includes whānau, friends, neighbours, hapū, iwi and the communities where people live and die. Care of the seriously ill person’s hinengaro (mind/emotions), tinana (body), wairua (spirit) are taken care of as well as the needs of their immediate whānau (family) who experience loss and grief. *Walking Sunny Home* highlights that whānau are actively involved in palliative care. Whānau often provide most of the care at the end of life. Sometimes only one or two people may be personally involved in the actual day-to-day care however, some whānau may have many people involved. Individuals often work to their strengths and provide practical support such as attending medical appointments or taking turns to companion the ill and dying person. Whānau may also provide help with housing or finances.

## **PALLIATIVE CARE PROVIDED BY HEALTH PROFESSIONALS AND HOSPICE**

Whānau are supported by a range of health professionals including the ill person’s GP, their local hospital or hospice or an Aged Residential Care facility if that is the person’s home. Indeed, any individual or health professional who engages in supporting someone who has a serious illness has a responsibility to provide palliative care. Hospice is a specialist palliative care service.

Hospice staff are experts at supporting seriously unwell people and their whānau to navigate their way through a serious illness and death. This is incredibly helpful as caring for someone who is dying is one of the most challenging things whānau will experience.

Some Māori whānau shy away from accepting support from their local hospice because they think hospice is a place where people go to die, however, the purpose of hospice is to help people live for as long as they can at home, and to die at home if that is their wish. Sometimes people may have need of medical support requiring them to be hospitalised in a hospice inpatient unit or in a hospital. Not all hospices have inpatient units (beds) where people can stay to receive support to manage symptoms or to receive respite. Hospices can offer all sorts of support, especially when people have complex health issues. They also provide equipment, resources and bereavement support as needed. Hospices have a vital role providing palliative care education in the community.

## CONVERSATIONS ABOUT PALLIATIVE CARE

We hope *Walking Sunny Home* will encourage whānau to engage in conversations about palliative care and to discuss what people want at the end of life. Regardless of whether people want a natural death or an assisted death, everyone is entitled to receive palliative care at home, in hospital, in an Aged Residential Care home or in a hospice. A person who has a terminal illness will need to consider carefully all the options available to them, including palliative care or assisted dying (whānau are familiar with the term 'euthanasia' or ending a person's life to relieve suffering).

## Key messages in *Walking Sunny Home*

Sunny's husband Mana reflects on his wife's unexpected illness, diagnosis and death. People often think their illness is caused by an existing health condition and they can delay seeking help. It can come as a huge shock when a terminal diagnosis is revealed. Whānau are often unprepared for the news.

Our aim in this book is to show what palliative care looks like by illustrating the care that Sunny received following her terminal diagnosis. For example, Sunny's māmā and pāpā came to support her. Also, Mana and their three rangatahi (teenagers) were by her side the entire time.

We wanted to show how Sunny and her whānau were supported by their local hospice who provided great palliative care at home. We wanted to show how beneficial it was when the hospice nurse and the kaiwhakahaere (advocate) regularly visited Sunny at home.

## PŌURITANGA - SADNESS AND GRIEF

Sunny's biggest concern was not for herself but for her children, especially her son Iraia. Iraia was withdrawn and his silence and mamae (emotional pain) was a concern for everyone. The whānau tried to support Iraia by encouraging him to talk about his feelings; they knew talking about his feelings would help him begin to release his mamae (emotional pain), frustration and anger.

## LOVE NEVER ENDS

This is a pūrākau about aroha (love, concern and empathy) and celebration. Sunny's whānau believe she will live on eternally, not only in the universe but in their hearts, minds, and wairua (spirits). In the final scene, Mana's whānau illustrate the ritual of saying 'goodbye' during the period of Matariki.

Matariki signals the end of one year and the start of the Māori New Year. During Matariki Te Waka o Rangi (the canoe of the sky) can be seen on the early morning horizon; it is captained by Taramainuku. During the previous year Taramainuku gathered up all the wairua (spirits) as they left their bodies and he placed them in his net.

As sunrise approached Mana encouraged his children to call out their mother's name as Taramainuku released the wairua he had gathered from his net. As each wairua slipped silently from his open net they took their place in the early morning sky. The whānau were transfixed as they watched Sunny transform into a brilliant whetū (star) that cracked open the darkened sky. Their tears fell heavily like rain drops on newly planted seeds. Mana knew these seeds were called 'hope' for a better year ahead.

## WHAKATAUKĪ

Kia Whakatōmuri te haere whakamua

*Walk backwards into the future with eyes fixed on the past.*

# 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](mailto:AssistedDying@tewhatuora.govt.nz)



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