

He Waka Kakarauri



Rarangi Tohutohu o te Waka Kakarauri
Guidelines for Engaging Māori in Advance Care Planning Conversations

Acknowledgements

The Northland Māori Advance Care Planning (ACP) Working Group wishes to thank and acknowledge the many people who have provided advice, input and review during the development of this guideline.

Special mention and thanks go to:

Ned Peita for the carving and waka model korero and the Northland District Health Board Kaunihera Kaumātua for the naming and blessing of He Waka Kakarauri.

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He Mihi – Greetings

Tena koutou nga morehu o nga maataa waka, mai i te ao tawhito. Kei te mihi atu; kei te tangi atu ki nga mate kua mene atu ki te po.

Ratou nga manu tioriori o nga pari karangaranga me nga kaka wahanui o te wao nui a Tane.

E te hunga kua whakawhiti atu ki te Ao Wairua, tena koutou katoa. Kua Tangihia, kua mihia, me ki, kua ea te wahanga ki a ratou.

Koutou nga mahuetanga iho i a ratou ma, tena koutou, tena koutou katoa.

He Whakarapopotanga – Foreword

I have been asked to pen this foreword, on behalf of the Northland District Health Board Kaumātua Kaunihera, for “He Waka Kakarauri” – a model to engage Māori in conversations that are important for future health and end of life care needs.

It is our hope that this model will encourage conversations about our health – when we are well and when we are sick or dying – that are tika (are right), pono (are true) and aroha (shared with love), and are held at a time and in an environment that is culturally appropriate to Māori.

We want to especially acknowledge the collective efforts of the Northland District Health Board Nursing and Midwifery Directorate, the Māori advance care planning steering group, the Māori Health Directorate, Māori consumer representatives, healthcare workers and Māori whānau, who, over the past years, have talked, cried, sung, reflected, revised and devoted much of their heart and soul into designing this model.

This comment expresses many of our thoughts: “This is the first model that I have seen in a long time that places the wairua (spirituality) back into health conversations,” and for this we are eternally grateful.

Na

Kaumātua Te Ihi Tito on behalf of the Northland District Health Board
Kaunihera Kaumātua

Tena koutou, tena koutou katoa.

Ko te pae tawhiti, whaaia kia tata

Ko te pae tata, whakamaua kia Tina! Tina!

Māori ACP Guide Development

Advance care planning (ACP) is a process of discussion and shared planning for future health and end of life care. It involves the patient, their whānau and healthcare workers.

Several researchers in New Zealand have explored Māori and whānau experiences of palliative and end of life care; findings suggest that there are differences in the uptake of ACP across cultural groups in New Zealand.

Northland District Health Board was tasked by the National ACP Cooperative to lead the work with Māori consumers and healthcare workers to develop culturally appropriate resources which meet the aspirations of Māori patients and whānau. In 2014, a Northland Māori ACP Working Group was established and, in 2015, the Working Group hosted two co-design hui to consult with consumers and healthcare workers.

The consultation confirmed that ACP is important to Māori and that there is a need to engage Māori patients and their whānau in a culturally appropriate manner when discussing future health and end of life care needs. Throughout this resource the term 'Māori whānau' has been used to reflect the voice of those who provided input into the development of the Waka Kakarauri model.

Acknowledging earlier work undertaken by the original Northern Region Māori ACP Tool Task Team and Kia Ngāwari study participants, the Working Group recommended the waka model for consideration as a tool to engage Māori in ACP. This concept was well received by participants of the co-design hui and received further support from members of the former regional team.

In early 2016, the Working Group developed this guide as a resource for Māori patients, whānau and healthcare workers to use when engaging in advance care planning conversations. The waka images used in this guide are of a waka carving which was generously gifted to the ACP programme by Ned Peita from Ngāti Hine.

We hope you find this to be a valuable and informative resource.

Nga mihi

Northland Māori ACP Working Group

Introduction

“Kia tika te wā; kia tika te wāhi. Kia tika te tangata; kia ora te whānau.”

*Whānau will thrive and flourish, with the right people,
in the right place, at the right time.*

Moe Milne, 2015

The Waka Kakarauri model outlines a framework for Māori to encourage advance care planning conversations, within the context of health – living well, when someone is sick, when a loved one is dying or has passed away.

It draws on the Te Whare Tapa Wha model, designed by Professor Mason Durie, and will be useful as a ‘starting point’ for Māori individuals, Māori whānau (family), friends, healthcare workers and ACP trained practitioners to have culturally appropriate conversations.

Guide Purpose

Korero mai - Korero atu (Speak inwards - Speak outwards)

Māori forms of communicating were, and in some areas, still are primarily oral. Communication was expressed through whaikorero (story telling), waiata (song), whakataukī (proverbs) and by whakapapa (genealogy). There is sentiment attached to the voice and face-to-face communication; hence the emphasis is on conversations. It is not easy to start an advance care planning conversation; however Māori whānau in Northland advised that it was important to start the conversation about planning for the future and end of life care.

Māori whānau told us that, “Māori do death well, but not dying.” For example, many Māori can identify the marae (meeting house) and urupaa (cemetery) where they will lay in state and ultimately be buried. In addition, when a member of a whānau dies, the community automatically kicks into action to ensure all aspects of the tangi (funeral) are organised; roles are predetermined and understood.

However, when it comes to the hours, days or months before death, whether known or unknown, Māori are not always confident about discussing and sharing what their wishes are when they receive a poor prognosis (news and information) about their health status and are needing to plan and make decisions. A Māori health professional urges Māori whānau to have these discussions prior to presenting at an emergency department or admission to hospital when emotions are high and it is challenging to have a conversation or make decisions about health planning and end of life care.

Guide Structure

He Waka Kakarauri is comprised of several components that reflect the parts of a waka; each of which has an important role in advance care planning for Māori.

- Kaihautu (the leader), representing ko au (me)
- Kaihoe (paddlers), representing whanaungatanga (relationships)
- Te Hiwi (hull of the waka), representing tinana (body)
- Te Tau Ihu (prow), representing wairua (spirituality)
- Te Tau Rapa (stern), representing hinengaro (mind)
- Moana/Awa/Puna (the ocean, river or spring), representing the patient's ACP journey

The model encourages patients to think about “Three things that matter to me” in relation to each component of their waka. The guide explains the significance of each component and how it relates to the patient's ACP journey. Each section contains information for patients, their whānau and healthcare workers. A tear-out patient resource is also included in the guide.

What is Advance Care Planning?

Living for today, planning for tomorrow

Advance care planning (ACP) aims to ensure patients feel better informed about future care and treatment choices; and healthcare workers are better informed about patient's care preferences, particularly around future health and end of life care.

The value of ACP lies in the shared conversations and decision-making between an individual and healthcare workers responsible for that person's care. It should also involve the person's whānau and/or carers if that is the person's wish.

As part of the ACP process, a person may choose to share their wishes, preferences and personal goals in a written Advance Care Plan. This plan may be changed at any time the person wishes to do so. Whether a written Advance Care Plan is completed or the patient verbally shares their wishes, healthcare workers will endeavour to honour the wishes and preferences of the patient. It is not just the destination (i.e. a written care plan) but the journey (the shared conversations and decision making) that is important in the ACP process.

What matters to you?

ACP gives everyone a chance to say what is important to them. Korero (talk and discuss) with your whānau, friends and healthcare workers about your wishes and health needs while you are able to and not just when you are nearing the end of life.

You can't control when you get sick and for how long, but you can make sure your whānau, friends and healthcare workers know how they can look after you – particularly if you can no longer speak for yourself. And the good news is, you can korero with them today. It makes it much easier for whānau, friends and healthcare workers to understand:

- Your treatment views
- Your spiritual/religious views
- Your emotional views
- Your whānau support views

ACP for Māori

An assumption that advance care planning is a simple and easy process would be wrong – it needs considerable skill and sensitivity due to the deep significance of the subject.

ACP benefits patients by improving healthcare planning and end of life care. The planning process assists the individual to identify their personal beliefs and values and incorporate them into plans for their future healthcare.

The Waka Kakarauri model has been designed as an engagement model to help patients, whānau and healthcare workers think about, talk about, and plan for future healthcare from a Māori world view. The guide may not answer all your patai (questions), which is where korero and guidance from healthcare workers play a key role. Some people like to write down or take notes, while others don't; what is important is the conversation.

Key factors identified as being important to Māori when engaging in ACP conversations include:

Te Ao Hurihuri – Like the changing world around us, Māori are dynamic and vibrant people. Mason Durie notes that Māori are not a homogenous culture¹, meaning that there is variation on how Māori view the world and their understanding of Māoridom. For healthcare workers, caution should be taken not to make assumptions about whether Māori speak te reo (language), know their whakapapa (heritage, ancestors) or practice tikanga and kawa (cultural practices).

Tapu – Māori whānau advised that discussing future healthcare needs and, in particular, end of life care can be a tapu (sacred) subject. Therefore consideration is needed whether patients feel comfortable talking about this subject in the presence of kai (food).

Karakia – A prayer and translation is offered within this guide to start and finish an ACP conversation. Karakia is not primarily the domain of religion; karakia can be about acknowledging the elements and creating a safe environment to go about our daily activity. A karakia could be offered, but again, it should not be assumed that all Māori would want to start an ACP conversation with a karakia.

Manaaki – Initiating conversations about advance care planning is not an easy topic to start. The importance of whānau, family and healthcare workers supporting the patient when discussing advance care planning cannot be under-estimated. In discussing future health needs and end of life care, the patient may need assistance with options available and medical language.

Sample Karakia for ACP

Ma te ra e kawē mai te ngoi ia ra, ia ra
 Ma te marama e whakaora i a koe i waenga po,
 Ma te ua e horoi ou maharahara,
 Ma te hau e pupuhi te pakahukahu ki roto i to tinana,
 I roto i ou hikoitanga i te ao,
 Kia whakaora koe ki te humarie ataahua hoki o ou ra
 Mo ake tonu atu

Amine

May the sun bring you energy by day
 May the moon softly restore you by night
 May the rain wash away your worries
 May the wind blow new strength into your being
 May you walk on this earth in peace all the days of your life
 and know its beauty forever and ever

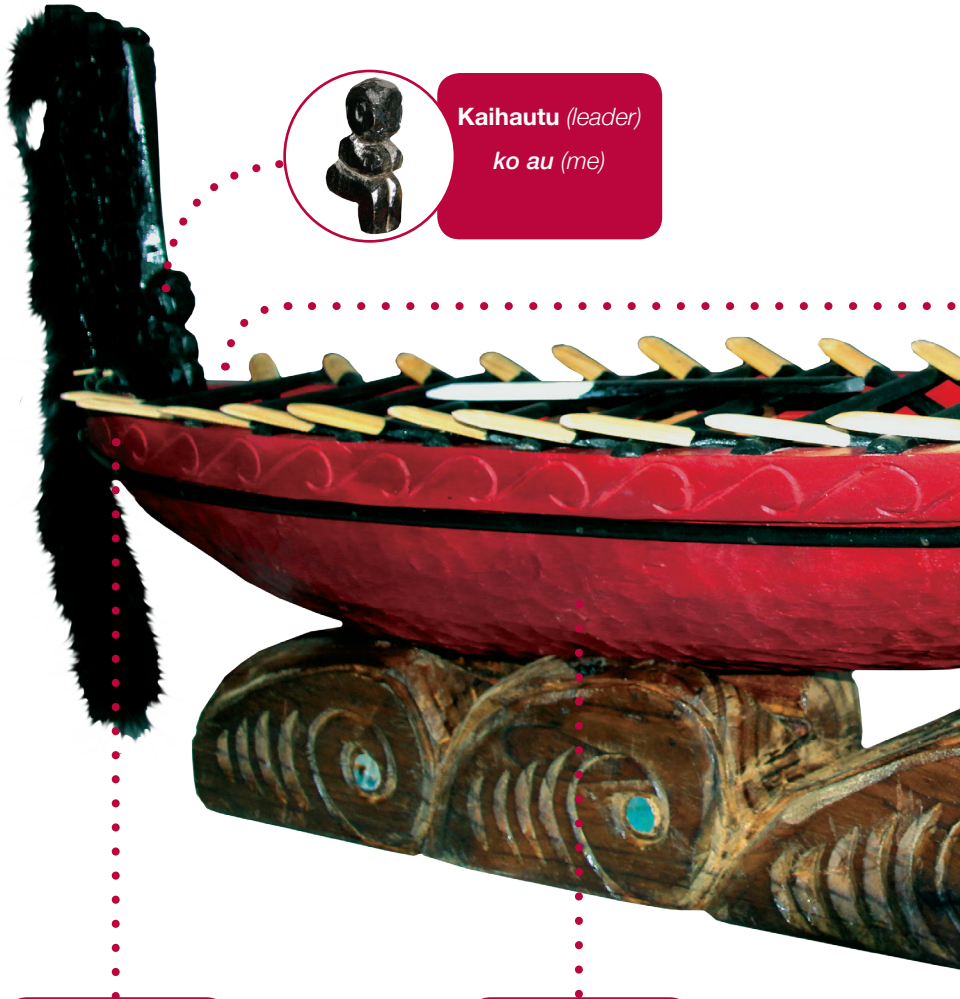
Amen

¹ Durie, M. 2006. *Measuring Māori Wellbeing*. New Zealand Treasury Guest Lecture Series. Wellington.

Rarangī Tohutohu o te Waka Kakarauri

He kaupapa hauora puta noa, ma te waka Kakarauri e kawē.

Kakarauri wairua time, the ending of darkness and the beginning of light, or vice versa. Ka huri.



Kaihautu (*leader*)

ko au (*me*)

Te Tau Rapa (*stern*)

hinengaro

(*mind/wellbeing*)

Te Hiwi (*hull*)

tinana

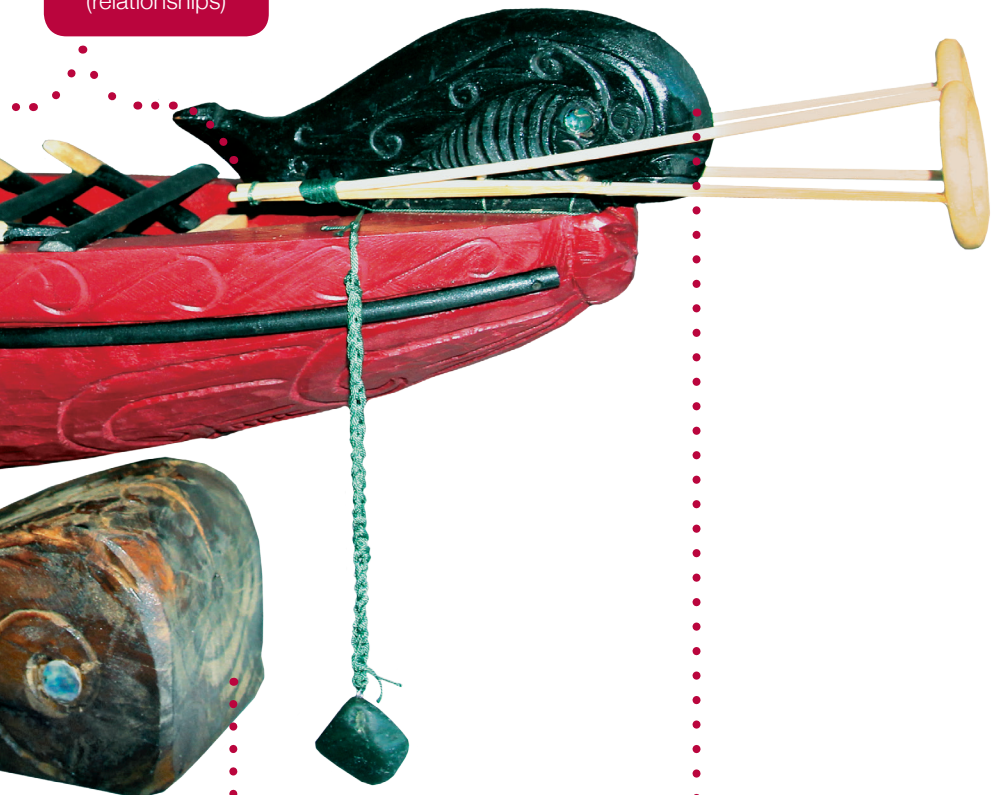
(*body*)

Te Waka Kakarauri acknowledges the conversations that are important for future health and end of life care needs.

Haere ki te po nui, te po roa, te po whaka uu ai ta koutou moe.

Kia puta ki te whei ao, ki te ao marama

Kaihoe (*paddlers*)
whanaungatanga
(relationships)



Moana/Awa/Puna
(*Ocean/River/Spring*)
(journey)

Te Tau Ihu (*prow*)
wairua
(spirituality)

Kaihautu (the leader), representing Ko Au (me)



The Kaihautu is the leader or navigator of the waka. Ko au is 'me' and refers to the patient who is at the center of the advance care planning process and is in charge of navigating their own journey; they are the 'boss' of their waka.

While you are still strong and able, it is a good idea to start thinking about your future healthcare needs and make your preferences known to your whānau and healthcare workers.

We have suggested the Waka Kakarauri as a way to start your conversations. We want to know what matters to you: what are your wairua-spiritual, hinengaro-emotional, tinana-physical and whanaungatanga-relationships, values and beliefs? If we know what your needs, queries or concerns are then your healthcare workers and whānau can make sure that your dignity is upheld and your wishes are respected at all times.

Korero mai – Korero atu!

Consider if you became unwell and could not speak for yourself – what would you want your whānau and healthcare workers to know about you? What matters to you?

Three things you need to know about me or what matters to me:

I am Māori...

I have specific cultural needs...

I belong to...

What tikanga beliefs and values matter to you?

- Wairua (spirit, soul)
- Hinengaro (mind, intellect, awareness)
- Rongoa (treatment, solution, tonics)
- Mauri ora (cultural identity)
- Whānau (family group)
- Other

Notes for Kaihoe (support people)

- Remember, this is about the patient's journey and their wishes and it is all about what matters them.
- Time and place are important, so consider the setting in which ACP is discussed and check in with the patient that they are comfortable to proceed.

“Ma mua ka kite a muri: ma muri ka ora a mua.”

Those who lead give sight to those who follow. Those behind give the life force to those ahead.

Tipu Ake Leadership Model, Te Whaiti Nui Life cycle, 2001

Kaihoe (paddlers), representing Whanaungatanga (relationships)



The patient is in control of their waka and at times needs support from whānau and healthcare workers as the Kaihoe (paddlers) of the waka. All those in the waka are journeying with and alongside the patient and are there to support. The Kaihoe role is further referred to in the guide as support people.

Whanaungatanga focuses on the nature of interpersonal relationships, within the family and beyond. Whānau and friends can provide strong support, ask questions that you may be too shy to ask and seek advice as appropriate. You may have several healthcare workers as you navigate through your health journey and making sure that they understand what matters to you is important. You can talk to your GP, specialists, nurses or other members of the healthcare team to explore treatment options and to translate medical language.

Three things that honour my whanaungatanga:

Who do you want in your waka?

- Whānau
- Friends
- General Practitioner (GP)
- Nurses
- Specialist
- Healthcare team
- Other

Start thinking about all the people in your life and identify their qualities and how they can support you:

- Who is kind, loving and forgiving?
- Who can you rely on to get you to appointments?
- Can someone move into your home to look after you?
- Who makes nutritious kai?
- Who likes to ask all the questions?
- Who will be 'straight up' with you?

Maybe there is one person; maybe this person is a whānau member or friend or maybe you have lots of whānau who can support you at different parts of your health journey. It is always helpful to identify a key spokesperson who may speak for you on your behalf in the event you can't.

If you have appointed an Enduring Power of Attorney (someone who legally represents your personal care and welfare), you must discuss your wishes with them so that they can make good decisions on your behalf if they ever need to.

Notes for Kaihoe (support people)

- Identifying a key spokesperson from the whānau and for the patient is important, particularly in an acute hospital setting where the patient may not be able to speak for themselves.
- The patient may want someone to be with them at GP visits, ward rounds or when a district nurse visits them at home.

"He waka eke noa."

We are all in this together.

Te Hiwi (hull of the waka), representing Tinana (body)



For Māori, physical well-being is intertwined with spiritual, emotional and family well-being. An example of the connection between physical well-being and spiritual well-being is how all things connected to the body are tapu (sacred). It is believed that a breach of tapu contributes towards illness.

Te Hiwi refers to the hull or foundation that supports the waka. In this model, it represents the tinana, or physical health and well-being. Attached to the hull or foundation is the Tau Manu (anchor) that strengthens the hull and the kaupapa in this instance is advance care planning.

Te tinana relates to the physical component of an individual, the body. A lot of people take their physical health for granted and it is only when it starts failing us that we begin to appreciate what we have.

Three things that honour my tinana:

To help us understand what is sacred to you, please let us know if any of the following are important to you and your whānau:

- Your head is tapu (sacred) and must be regarded with respect
- You need to be washed in a particular way or prefer whānau to do this
- You would prefer to be cared for by a mokopuna or another whānau member
- You want to take rongoa Māori with your prescribed medication
- You may want to discuss resuscitation with your healthcare team
- You want a second opinion
- You may want to consider organ donation

Notes for Kaihoe (support people)

- Be mindful of the cultural and gender appropriateness in caring for Māori; suggest referring to your organisational tikanga best practice guidelines.
- Being respectful of the conversations with Māori about death and dying as this is deemed a tapu subject.

*“Kia rongo koe te kiki, te kaka, a na rau a te waka,
ka mohio koe i te kaha a te waka.”*

*When you hear the grinding of the lashings of the waka
you understand its strength.*

Ned Peita, 2016

Te Tau Ihu (prow of the waka), representing Wairua (spirituality)



The prow of the waka opens the way to the future. The significance of the Tohorā (whale) at the front of the waka represents their Kaitiaki (guide) role. The Karu Atua are the guiding eyes through the ups and downs in life, but keep us heading in the right direction with a clear pathway inclusive of goal setting and care planning.

Taha wairua has been identified as being the most essential requirement for health. Taha wairua is not just about religion; it refers to spiritual awareness and our relationship with the environment and cultural identity. The breakdown of this relationship could be seen in terms of ill health. When you are unwell, we need to know how we can honour your spiritual and religious beliefs.

Three things that honour my wairua:

Please tell us if:

- You have spiritual and/or religious practices that you would like to be respected, such as a karakia (prayer) before and after discussing ACP.
- Specific rituals must be performed before you enter the hospital, have surgery, or before you discuss anything to do with your health.
- You would like access to a Kaumātua or Kuia for support.
- You prefer to keep your beliefs private and you do not want cultural support from anyone who is not from your whānau, hapu, iwi or hāhi (church).

Notes for Kaihoe (support people)

- A karakia is offered within this guideline, however do not assume that all Māori will want to have or recite a karakia.

“The future is not something we enter – The future is something we create.”

Mason Durie, Pae Ora Māori Health Horizons, 2009

Te Tau Rapa (stern), representing Hinengaro (mind)



Te Tau Rapa (the stern) ensures the waka progresses steadily and safely and also assists in the direction of the waka. It involves history and background; this is what guides the waka.

Taha hinengaro refers to thoughts, feelings and behaviour which are vital to well-being. Communicating through emotions is important and often more meaningful than the exchange of words or writing it down, and is valued just as much. For example, if someone is admitted to hospital, then whānau will visit in great numbers. This is how Māori express their love and respect. What other examples do we need to know about you and your whānau?

Three things that honour my hinengaro:

- Tell us who you would like to have with you. Sometimes hearing your whānau talking, singing, crying and laughing will help you feel better.
- On the odd occasion you may need some ‘alone time’ or you may want to keep your health information private, we will respect your wishes and let your whānau know this.
- Prayer and/or meditation, yoga or music may assist in easing the mind and to help you feel more relaxed.
- Consider that if or when you cannot speak for yourself, who will speak on your behalf?

Notes for Kaihoe (support people)

- The patient and whānau may need some guidance on the difference between an advance directive and an advance care plan. An Advance Directive is a legal document while an Advance Care Plan is a process which may result in a written document that reflects the patient’s thinking and wishes around future health and end of life care.
- Appointing an Enduring Power of Attorney (EPOA) is a legal process that formalises an individual identified by the patient who will manage their affairs and speak on their behalf if they can no longer speak for themselves.
- More information can be found on the national Advance Care Planning website: <http://www.advancecareplanning.org.nz>

“He taonga rongonui te aroha ki te tangata.”

Goodwill towards others is a precious treasure.

Moana/Awa/Puna (the ocean, river or spring), representing the patient's ACP journey



The moana/awa/puna represents the journey of life or location which, like these waterways, is fluid and moves and changes with the current and weather.

The waka is mounted on three waves: ngaru nui (the big wave), ngaru roa (the long wave) and ngaru paewhenua (the wave that brings the waka to shore). This reflects the nature of advance care planning – that the discussion or even what is written in a document is not the end result; it is continually evolving and is a work in progress which can change depending on circumstances.

Three things that honour my health journey:

If you were to write an Advance Care Plan, where would you store it? An Advance Care Plan is an important document and belongs to you, for you to share with your whānau and healthcare workers.

Notes for Kaihoe (support people)

- Māori whānau have advised that they prefer to korero rather than writing down their thoughts and wishes in a document. There is also some concern that, if writing things down, this would be taken as a final decision and there would be no option to change. Patients need to be reassured that they can change their Advance Care Plan at any time. Remember that the journey is just as important as the destination.

*“Kua tawhiti ke to haerenga mai, kia kore e haere tonu.
He tino nui rawa ou mahi, kia kore e mahi nui tonu.”*

*You have come too far, not to go further.
You have done too much, not to do more.*

Ta Himi Henare, Ngati Hine, 1989

Glossary

Aroha	Love
Awa	River
Hinengaro	Emotions or Intellect
Kai	Food
Kaihautu	The leader
Kaihoe	Paddlers
Kaitiaki	Guide
Karakia	Prayer
Kaupapa	Purpose
Ko au	Me
Korero	Talk / discuss
Marae	Meeting house
Mauri ora	Cultural identity
Mihi	Greetings
Moana	Ocean
Ngaru	Wave
Patai	Questions
Pono	True
Puna	Spring
Rarangī Tohutohu	A list of standards
Rongoa	Traditional treatments
Tangi	To mourn
Tapu	Sacred
Te Hiwi	Hull of the waka
Te Tau Ihu	Prow of the waka
Te Tau Rapa	Stern of the waka
Tika	To be correct
Tikanga	Cultural practices
Tinana	The body
Urupaa	Burial ground
Waiata	Song
Wairua	Spirituality
Waka	Canoe
Whaikorero	Eloquent language using imagery, metaphor, whakataukī, pepeha
Whakapapa	Genealogy
Whakataukī	Proverbs

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