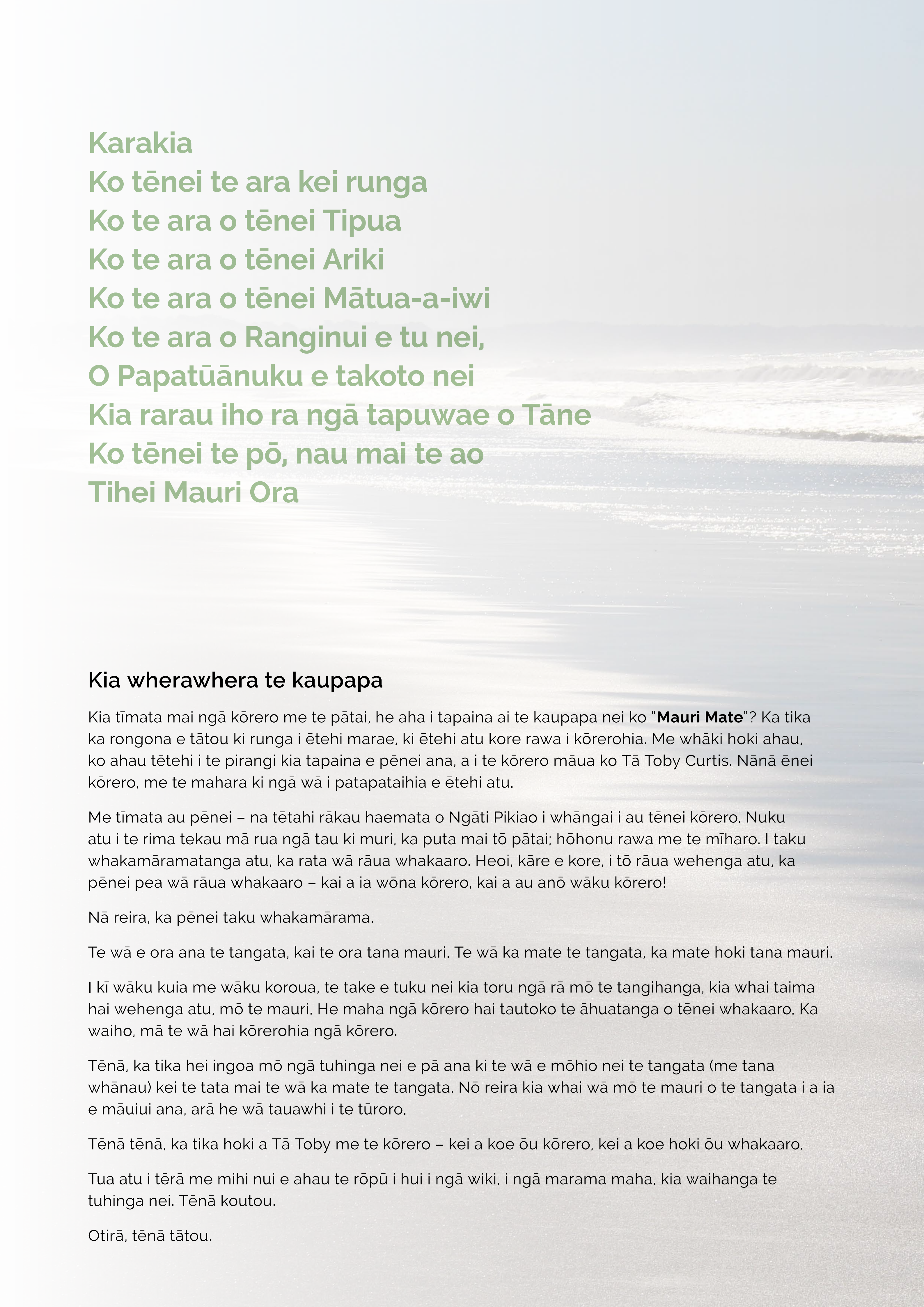
Mauri Mate

A Māori Palliative Care Framework for Hospices

Te Ohu Rata o Aotearoa
Māori Medical Practitioners

2019



Karakia

Ko tēnei te ara kei runga
Ko te ara o tēnei Tipua
Ko te ara o tēnei Ariki
Ko te ara o tēnei Mātua-a-iwi
Ko te ara o Ranginui e tu nei,
O Papatūānuku e takoto nei
Kia rarau iho ra ngā tapuwae o Tāne
Ko tēnei te pō, nau mai te ao
Tihei Mauri Ora

Kia wherawhera te kaupapa

Kia tīmata mai ngā kōrero me te pātai, he aha i tapaina ai te kaupapa nei ko "**Mauri Mate**"? Ka tika ka rongona e tātou ki runga i ētehi marae, ki ētehi atu kore rawa i kōrerohia. Me whāki hoki ahau, ko ahau tētehi i te pirangi kia tapaina e pēnei ana, a i te kōrero māua ko Tā Toby Curtis. Nānā ēnei kōrero, me te mahara ki ngā wā i patapataihia e ētehi atu.

Me tīmata au pēnei – na tētahi rākau haemata o Ngāti Pikiao i whāngai i au tēnei kōrero. Nuku atu i te rima tekau mā rua ngā tau ki muri, ka puta mai tō pātai; hōhonu rawa me te mīharo. I taku whakamāramatanga atu, ka rata wā rāua whakaaro. Heoi, kāre e kore, i tō rāua wehenga atu, ka pēnei pea wā rāua whakaaro – kai a ia wōna kōrero, kai a au anō wāku kōrero!

Nā reira, ka pēnei taku whakamārama.

Te wā e ora ana te tangata, kai te ora tana mauri. Te wā ka mate te tangata, ka mate hoki tana mauri.

I kī wāku kuia me wāku koroua, te take e tuku nei kia toru ngā rā mō te tangihanga, kia whai taima hai wehenga atu, mō te mauri. He maha ngā kōrero hai tautoko te āhuatanga o tēnei whakaaro. Ka waiho, mā te wā hai kōrerohia ngā kōrero.

Tēnā, ka tika hei ingoa mō ngā tuhinga nei e pā ana ki te wā e mōhio nei te tangata (me tana whānau) kei te tata mai te wā ka mate te tangata. Nō reira kia whai wā mō te mauri o te tangata i a ia e māuiui ana, arā he wā tauawhi i te tūroro.

Tēnā tēnā, ka tika hoki a Tā Toby me te kōrero – kei a koe ōu kōrero, kei a koe hoki ōu whakaaro.

Tua atu i tērā me mihi nui e ahau te rōpū i hui i ngā wiki, i ngā marama maha, kia waihanga te tuhinga nei. Tēnā koutou.

Otirā, tēnā tātou.

The Framework

Mauri Mate – A Māori Palliative Care Framework for Hospices was commissioned by Totara Hospice (South Auckland) jointly with Mary Potter Hospice (Wellington). A companion document to this framework, is **Māori and Palliative Care, Literature Review Report for Te Ohu Rata o Aotearoa** (2018), authored by Kat Mason and Dr Tess Moeke-Maxwell, Palliative Care and End-of-Life Research Group, School of Nursing, Faculty of Medicine and Health Sciences, University of Auckland. The Literature Review was completed in May 2019. Updates have been provided where needed.

Te Ohu Rata o Aotearoa (Te ORA) – Māori Medical Practitioners Association

Te ORA is a professional body representing Māori medical students and doctors working as clinicians, researchers and teachers. With approximately 340 active members, Te ORA represents the majority of the Māori medical workforce. Te ORA's vision is to provide Māori medical leadership to the health sector to effect Māori health development.

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Cover Photograph courtesy of Clare O'Leary – Wellington

Project Sponsors

Totara Hospice (South Auckland)

Tēnā koutou katoa

Totara Hospice is committed to equity of access, experience and outcome for all Māori whānau who would benefit from great palliative care. We are committed to the needs of care being defined by those who receive it and to working in partnership to deliver that care and support in whatever place it is needed; community clinics, the inpatient unit or within a whānau's own whare. It was our view (amongst many of our partner organisations) that the Hospice sector has to step-up and reflect that it understands that equity of care is not a one size fits all approach. Equity of care is care that is regardful and valuing of difference.

Totara Hospice viewed the opportunity to engage with Te Ohu Rata o Aotearoa (Te ORA) and their wider network of Māori leaders in healthcare, research and academics as being fundamental to being able to act on our commitments and aspirations to provide culturally safe care; supporting our workforce to be active partners in the Treaty relationship.

The knowledge and wisdom the collective have so generously articulated in this expert framework – *Mauri Mate* – is a taonga for the sector to honour by putting it into practice within each and every Hospice across Aotearoa.

Our thanks to all the leading experts who gave of their time, their care and their knowledge in this work across Te ORA, Te Rōpū Taki Māori and Hospice NZ, our partners across palliative care places, places of learning and places of community. A special thanks to our sector partner Mary Potter Hospice Wellington, who shared a vison with us to do better.

Nāku iti noa, nā

Tina McCafferty , Chief Executive

Totara hospice
Living Every Moment

Mary Potter Hospice (Wellington)

Tēnā tatou katoa,

It was natural to respond to the karanga from Totara Hospice to participate in this project. Mary Potter Hospice sees the engagement of Te ORA and Māori doctors as an important step towards whānau receiving good palliative care where and when they need it. This resource provides tools to support Hospices in their planning and delivery of a service fit for whānau. It will support Hospices to meet Treaty commitments. Those that have contributed are respected in the field of Palliative Care – kaumātua, primary and community care specialists and those working hand in hand with whānau. This resource is designed to whakamana whānau. We hope it proves to be a valuable koha to enhance the manaaki of whānau at this most important time.

Kia tau te rangimarie,

Brent Alderton, Chief Executive

Mary Potter Hospice
With You

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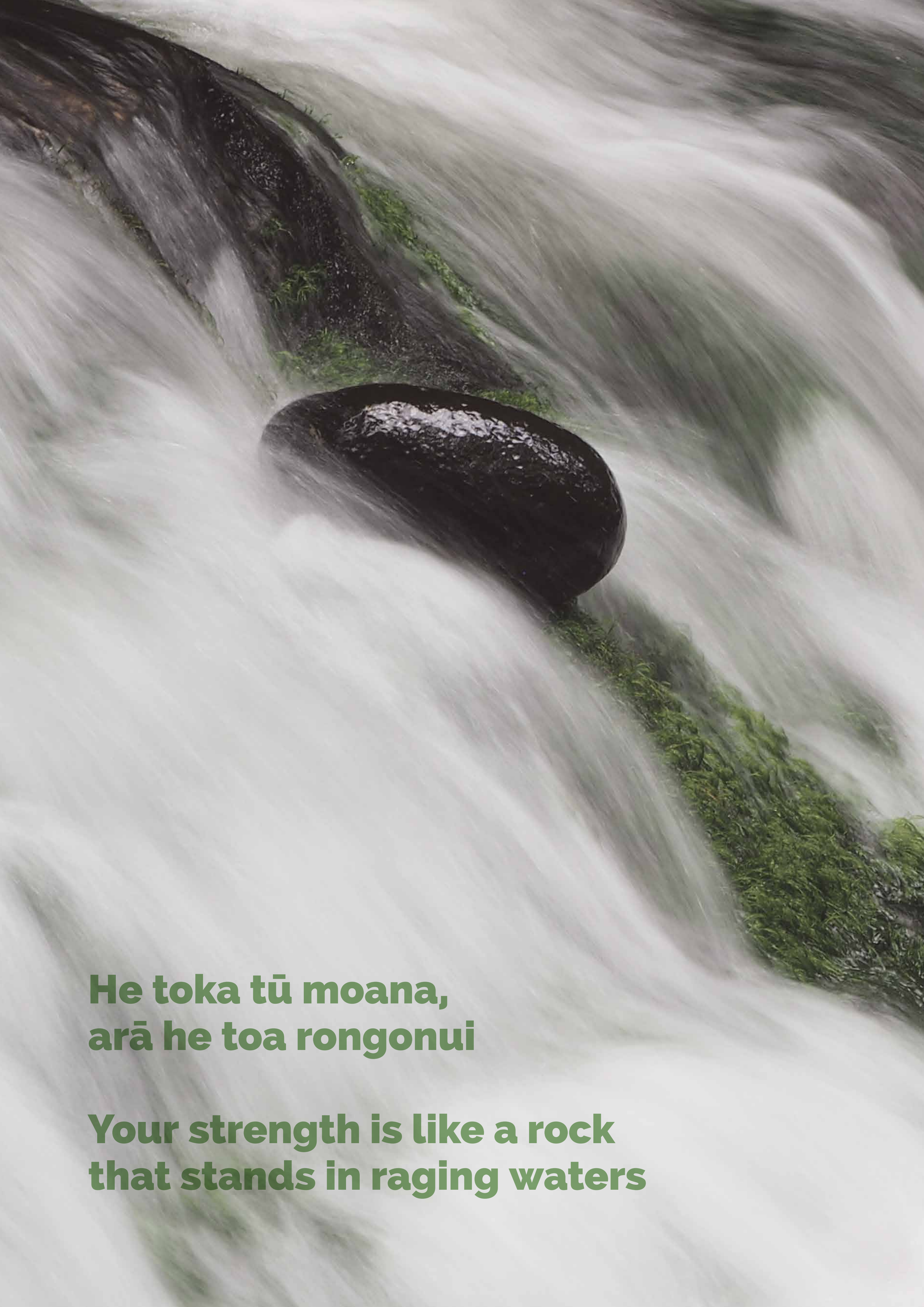

He toka tū moana,
arā he toa rongonui

Your strength is like a rock
that stands in raging waters

Wāhanga Tuatahi

Te Horopaki
Context

Te Pūtake o te Anga Pairuri Māori:
Purpose of the Māori Palliative Care Framework

This Framework responds to issues that Māori have raised with service providers and researchers. The aim is to develop guidelines for hospices, so adult Māori receive access to good palliative care which includes:

- good (quality) care in the lead-up to the end-of-life
- good comfort (compassionate) care at the end-of-life
- helpful whānau support during and after the illness, and the end-of-life (including spiritual care and grief support)

This document has been written as guidance for the hospices of Aotearoa. It is anticipated that this guide will be useful and adaptable for the services provided by primary care, aged residential care, hospital teams and whānau care.

This document refers to writings that have already been produced to assist hospices and palliative care providers, rather than repeating them. We have highlighted aspects that are relevant for the care of adult Māori and their whānau.

Whānau are at the centre of the Māori world and a Māori model of palliative care appropriately acknowledges the centrality of whānau. "Whānau" is not a straight translation of "family": it includes immediate family of children, mokopuna, siblings, spouses or significant others, and the wider whānau of cousins, aunts, uncles and kaumātua. The use of the term whānau in this document recognises the wide diversity of families within Māori communities and the differing resources and capacities to provide care to a dying loved one. Cultural practices can help sustain and strengthen whānau carers, increasing their resilience to cope with the many issues they will face.[1]

A contemporary view of whānau may include those who are not biologically related, but the support kinship is recognised – this is particularly relevant where those who need care, are estranged from whānau, or they are living away from whānau, or their whānau members are dispersed, living in other areas or countries.[2] [3]

Research highlights that many Māori, are not aware of what makes up 'palliative care' treatment or services. Māori do not necessarily know about the range of services provided through hospices and, as is common in the wider community, they tend to think of the hospice as dealing only with the 'last days of life', or a 'place to go and die'. Awareness promotion tailored especially for Māori is important, as is the written or video information.

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[1] Moeke-Maxwell, T., L. W. Nikora , N. Te Awekotuku. 2014, End-of-Life Care and Māori Whānau Resilience. Mai Journal, 3(2), 140 – 152

[2] Social Policy Research Unit – Ministry of Social Development. (2018). Families and Whānau Status Report 2018, Wellington

[3] The Whānau Rangatira Research Model, developed by Social Policy Research Unit (Superu) of the Ministry of Social Development, provides a useful way of framing Māori whānau research and focus.

Te Tiriti o Waitangi

Hospice New Zealand completed a review of the Hospice New Zealand Standards for Palliative Care in 2019. They make reference to the Treaty of Waitangi:

These standards align with the principles of the Treaty of Waitangi to work collaboratively with Māori to provide the best care and outcomes for Māori patients/tūroro and whānau.

Hospice New Zealand acknowledges the unique partnership with Māori as tangata whenua of Aotearoa/New Zealand. Hospice New Zealand acknowledges that hospices have a responsibility to ensure that quality compassionate palliative care is available and delivered to Māori patients/tūroro and whānau, alongside the care delivered to all members of the community.[4]

The Hospice New Zealand Standards reference a criteria for hospice to undertake Treaty training that will increase staff awareness on aspects of the Treaty, the issues facing Māori communities and to improve the service focus for Māori people and whānau.

Update Note: The Hospice New Zealand Standards were published and launched in May 2019 as; Ngā Paerewa Pairuri Tangata, Standards for Palliative Care 2019; available on request from Hospice New Zealand using the following link; *https://www.hospice.org.nz/resources/standards-for-palliative-care/ or reading it via https://issuu.com/hospicenz/docs/hnz_standards_2019?e=7727130/70390948]*

The New Zealand Public Health and Disability Act 2000 also references the principles of the Treaty of Waitangi. The Guide to He Korowai Oranga, the Māori Health Strategy (2014), refers to these principles as Partnership, Participation and Protection. Using the principles is considered a basic approach by Māori communities, Māori health providers and many Māori health professionals. It is a useful place to start.

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[4] Hospice New Zealand. (2019). Ngā Paerewa Pairuri Tāngata, Standards for Palliative Care. (p8)

The Treaty Principles approach is outlined below:

He Korowai Oranga outlines the Treaty Principles applied in the health and disability sector:

Partnership: involves working together with iwi, hapū, whānau and Māori communities to develop strategies for Māori health gain and appropriate health and disability services.

Participation: requires Māori to be involved at all levels of the health and disability sector, including decision making, planning, development and delivery of health and disability services.

Protection: involves the Government working to ensure that Māori have at least the same level of health as non-Māori and safe-guarding Māori cultural concepts of values and practices.[5]

Another approach considered fundamental by many Māori in the health sector, is to focus on the articles of Te Tiriti o Waitangi (and emphasising the reo Māori version). The reo Māori version has primary recognition in international law as the language of those who signed the Treaty.[6] It is also perceived by Māori to have a stronger 'rights' base than the English version. The contemporary health claims being considered by the Waitangi Tribunal in 2018, would support quality palliative care for Māori as a right. The realisation of such rights is currently mediated by governmental capacity and funding and by the operational decisions of hospices on the allocation of resources. Such rights are also acknowledged in respect of other rights bearing on health, such as security, environmental wellbeing, and economic opportunity.

Update Note: The report of the Waitangi Tribunal is now published on-line as Hauora, Report on Stage 1 of the Health Services and Outcomes Kaupapa Inquiry, (2019).

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[5] Ministry of Health. (2014). The Guide for He Korowai Oranga, Māori Health Strategy

[6] Contra proferentem

A view of Te Tiriti o Waitangi

Article 1	the Crown guarantees governance (kawanatanga).
Article 2	guarantees specific protection of Māori treasures (te tino rangatiratanga... ō rātou taonga). We would assert that equitable, accessible and quality palliative care services for Māori whānau are viewed in this light.
Article 3	guarantees equal access for Māori under the law, and thus public services (ngā tikanga katoa rite tahi ki āna mea ki ngā tāngata o Ingarani).

These articles are a statement of responsibility to Māori in respect of palliative care. Yet the Ministry of Health acknowledges "limited access to specialist palliative care services, for example, in more isolated communities."[7] Palliative care is not exempt from issues of inequitable access to services for Māori. Article 3 of Te Tiriti obliges the New Zealand Government to increase resourcing for palliative care for Māori proportionate to their need.

Within palliative care, we assert that kaupapa Māori services are essential for the remedying of inequities. We currently do not have such services amongst hospices. Such models of care reflect the positive ideal set out in the Wai 262[8] (the claim into ownership and rights including Māori knowledge on fauna and flora) report, that "to acknowledge the importance of Māori culture and identity to Māori, is to acknowledge the importance of this culture and identity to the nation as a whole."

The variation in the views expressed in the boxed sections above, highlight why it is important for hospice and palliative care staff to undertake training of the Treaty – to understand the range of views amongst Māori. More importantly, it assists staff to understand the stress on quality palliative care services to Māori.

Update Note: The report of the Waitangi Tribunal is now published on-line as Hauora, Report on Stage 1 of the Health Services and Outcomes Kaupapa Inquiry, (2019).

Relevant to a discussion on applicable frameworks on Māori health perspectives and views, is the international United Nations document, The Declaration on the Rights of Indigenous Peoples, considers health issues amongst a wide range of social, cultural, natural assets and economic rights. The Declaration was adopted by the UN General Assembly in 2007. It was signed by New Zealand (by Hon Dr Peter Sharples) in 2010. The Declaration is being used in Aotearoa by Māori to 'shine a light' on the international context of indigenous health rights.

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[7] Ministry of Health. (2017). Review of Adult Palliative Care Services in New Zealand (p6), https://www.health.govt.nz/publication/review-adult-palliative-care-services-new-zealand

[8] Wai 262 was frequently referred to as the 'fauna and flora' claim. The Waitangi Tribunal in response to this claim, produced a wide-ranging report, 'Ko Aotearoa Tēnei', on the reform of laws, policies and practices, relating to health, education, sciences, intellectual property, indigenous fauna and flora, resource management, conservation, Māori language, arts and culture and involvement of Māori in the development of international instruments affecting indigenous rights.

The Māori Health Strategy, He Korowai Oranga was updated in 2014 and the Treaty Principles were articulated again. The strategy aims were expanded to include Pae Ora – healthy futures; elements of this aim are focused on continuing health and wellbeing of Māori individuals (Mauri ora), healthy Māori whānau (Whānau ora), and healthy environments (Wai ora). The pathways to achieving Pae Ora are particularly relevant for the hospice and palliative care sector (and is highlighted in this document);

- Development of whānau, hapū, iwi and Māori communities
- Māori participation in health and disability sector
- Effective health and disability services

Te Mana Taurite: Equity

The role of 'equity' or its perceived absence, has been the focus of work in the health sector, both nationally and internationally. 'Equity' as a concept is often confused with 'equality'.

An early 1990 definition produced for the World Health Organization described:

'The term inequity has a moral and ethical dimension. It refers to differences which are unnecessary and avoidable but, in addition, are also considered unfair and unjust. So, in order to describe a certain situation as inequitable, the cause has to be examined and judged unfair in the context of what is going on in the rest of society.' [9]

Further development of the concept of unfairness or injustice is reflected in definitions by Braveman and Gruskin (2003):

Inequities in health systematically put groups of people who are already socially disadvantaged (for example, by virtue of being poor, female, and/or members of a disenfranchised racial, ethnic or religious group) at further disadvantage with respect to their health; health is essential to well-being and to overcoming other effects of social disadvantage.[10]

We assert that hospices need to consider their practices or interactions with other providers, and actively assess whether their practice promotes equity or creates inequities.

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[9] Whitehead, (1990) "The concepts and principles of equity and health", a discussion paper for the World Health Organisation

[10] Braveman, P. and S. Gruskin. (2003). "Defining equity in health", Journal of Epidemiology and Community Health 57, (254-258). (p254)

Te Mahi Pairuri me Ngā Rōpū Ratonga Pairuri: Palliative Care and Hospice Services

Ngā Rōpū Ratonga Pairuri: Hospices

There are 33 hospice services around Aotearoa, with varying capacity (including a range of professional staffing), a varying mix of services (inpatient unit and community or home-based services, 'contracted beds' in residential facilities and/or services in aged care facilities), and regional spread (including rural and urban).

All hospices are charities supported with some DHB contract funding and a mix of fundraising; that is, all hospices operate with constrained budgets.

These limitations impact on hospice services. In order to deliver on these guidelines, hospices need to prioritise activities based on what can be delivered within current budgets and what could be considered as new activities in other phases. The aim of this document is to improve the Māori experience of palliative care, especially hospice palliative care.

The work of Professor Heather McLeod indicates that hospices are providing access to Māori patients relative to their national representation in the population. This analysis is based on the total hospice service for the country, which may distort the picture for individual DHBs. Nor does the data consider whether this is the right comparative base (for example, if the need is greater than that presented by the percentage of the population). Further analysis of Māori data may yet identify or highlight other issues. This Framework is however, informed by qualitative research to provide the evidence that will focus on improving the Māori experience of palliative care.

Hospices know that delivering high-quality services relies on good working partnerships with a range of services and communities. For Māori, the development of working relationships with iwi and Māori communities is critical, including Māori health and social services and providers. These relationships will assist Māori whānau to access hospice services, and support hospices in delivering quality services.

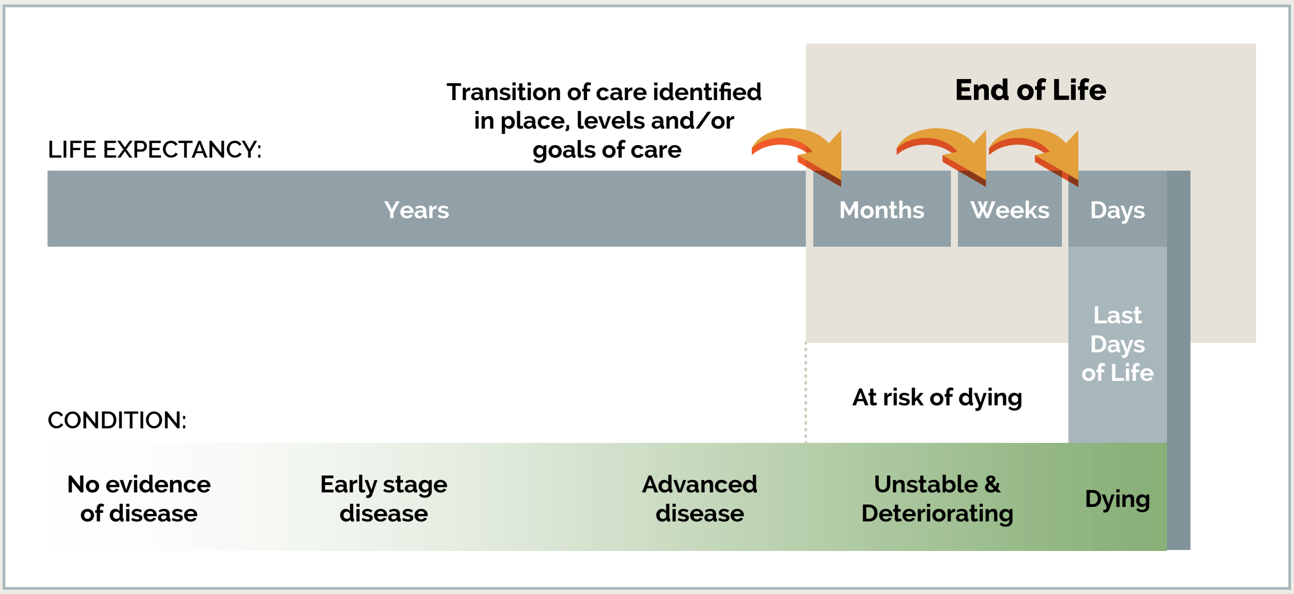
Te Mahi Pairuri: Palliative Care

Palliative care is often not well understood, even amongst health professionals. In some cases, it is believed to be just terminal care or end-of-life care, that it is the alternative to life-prolonging or curative care, that it is only provided by hospice or only for cancer patients.

While hospices have come a long way since the 2001 Palliative Care Strategy, the misunderstandings within Māori communities still persist and have tended to focus on the concept that the hospice is a 'place' to die, a place to go to (i.e. providing inpatient service) rather than a community service.

The following diagram used by the Palliative Care Council (2015) illustrates clearly the palliative care continuum that hospices work within. The time frame considered appropriate for most palliative care is up to a year before death, with the potential for intermittent assessment prior to this time frame especially for chronic conditions.

Figure 1: End-of-life and last days of life



Appendix 1 (page 58), outlines the two main definitions that are used to describe palliative care in New Zealand documents (the WHO definition and the New Zealand definition developed by the New Zealand Palliative Care Council). The definitions are well understood (and debated) amongst hospices so we do not intend to delve into the relative merits of the definitions.

It is not intended that the various illustrations and diagrams set out to describe palliative care in the literature be debated here. There are other depictions in documents used and valued by the hospice and palliative care sector. Figure 1 however, does illustrate that hospices are involved in providing care throughout the period leading up to the last days-of-life. During this period, a person is at risk of dying but will be living their life according to their capacity, capability and desire. This document is intended to cover the full spectrum of care represented in this diagram and provided by hospices.

Ko te Whānau te Aronga Nui: Whānau at the Centre

Whānau are at the centre of the Māori world, and a Māori model of palliative care will appropriately acknowledge the centrality of whānau. As described previously, whānau *'is not limited to traditional definitions but recognises the wide diversity of families represented within Maori communities… it is up to each whānau and each individual to define for themselves who their whānau is.'*[11] Whānau can include children, mokopuna, spouses or significant others, and siblings will play a crucial role before, during and after a person's end-of-life journey.

There is considerable variation in whānau: the size, number, members of whānau, to what degree they are connected with the palliative patient. Other factors include, the social complexity of their lives, the depth of involvement with 'te ao Māori', the ethnicity of spouse or partner (if applicable), whether there are other dependants, and whether they are physically distant or close. On occasion, the dynamics within a whānau may mean an individual Māori person with palliative care needs does not want to be cared for by their whānau.

How hospices communicate with whānau and Māori patients will be key in determining how the quality of the services will be received and whether the expectations of palliative care services that are effective, timely and culturally safe can be delivered. Facilitating large or small whānau meetings, spending time to understand the dynamics of each whānau, careful listening, attentive and inclusive planning with whānau, or checking with whānau for understanding – all of these may be useful or required. And, these approaches might need to be repeated as the whānau engagement changes over time.

Māori with a life-limiting illness and their whānau may experience spiritual difficulties, including challenges in and with their whānau, as well as psychological challenges including anxiety and depression.

In addition, the whānau member with a life-limiting illness will almost certainly experience symptoms such as; deteriorating mobility, pain, nausea, fatigue, and/or breathlessness. There are often social complexities and distress that needs to be identified and addressed.

Appropriate, timely management of all of these issues does require effective interdisciplinary teams working with patients and their whānau, in a variety of settings, including in their own home, hospital or in a hospice inpatient unit. The preferences of the patient and their whānau are paramount as services organise around them and help them understand the ever-changing options.

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[11] Ministry of Health. 2002. He Korowai Oranga Māori Health Strategy (p1).

Te Tūhonohono i Ngā Hapori Māori: Relationships with Māori Communities

Building relationships with Māori communities provides opportunity for partnerships and collaboration. Relationships with whānau, hapū, iwi and Māori providers may reveal insights into traditional Māori customs and local resources. Engaging in collaborative approaches to care may enhance quality palliative care that is culturally appropriate and provided in a co-ordinated way.

Good engagement and relationships with local Māori communities need to be seen as important partnerships as well as part of the communication channels for hospices. Not only is this a means of dispelling the myths about hospice (as an 'in-patient-only' service and a 'place' to die), it is a means of gaining support for the whānau (including the family member with a life-limiting illness) and a channel for sharing useful information and views on the hospice service.

Hospices will need advice and expert liaison to build such relationships. The priorities for local Māori at a 'governance' level will vary widely, as will the histories, the participation in social services, including health, and their involvement in Waitangi Tribunal processes or post settlement developments. Māori organisations also receive a wide variety of consultation processes from agencies which can be time-consuming for them. Their priorities may not be your service's priorities (and allowances need to be made for this around how consultation is carried out and the time frames for these processes).

Requested feedback from Māori whānau, Māori organisations, or community groups via consultation processes may be delayed or need more time.

Caution should be exercised with respect to no feedback – silence in a Māori setting does not usually convey agreement.

Agreement is usually conveyed directly and explicitly, and silence may suggest that further discussion, more time or appropriate opportunities to express concerns are needed.

The establishment of an advisory group is one approach to ensuring that relationships can be enhanced over time. Thought (and consultation) is needed in considering which groups might be approached to place a person on such a group and how the process will be initiated. Process is as important as context in this approach. Other approaches include tapping into existing Māori advice or health relationship groups.

Example One

Te Pou Tautoko – Mary Potter Hospice Māori Advisory Group

Te Pou Tautoko was established in 2008 to provide Mary Potter Hospice with Māori support and advice to deliver care to the communities it serves. The hospice acknowledges that the Māori members bring a unique set of skills and experience to the group. This tirohanga Māori (Māori world view) is what members offer. This brings an understanding of kaupapa tuku iho (inherited values) which informs tikanga (practice). This approach, alongside the hospice values, is to create safe practice for the care and to grow the bicultural competency of the hospice.

The members of Te Pou Tautoko are linked to iwi, to Māori/ iwi health providers, Māori communities, the Hospice Board and include kaumātua (kuia and koroua).

Te Pou Tautoko chose the phrase 'whetū i te rangi' as a philosophical by-line for the hospice to acknowledge "…that the stars are a spiritual connection to the cosmos. They provide… a navigational map to way-finders and travellers, keeping them safe…". They depict the concept of the patient as the 'star' – the focus of the service, and acknowledge the need to be alongside the whānau on the last journey of the patient. [12]

Te Pou Tautoko named their Hospice Strategy 2017 – 2022, 'Me aho mai ngā whetū'. Let the stars guide the way. This has also underpinned the translation of hospice values.

Example Two

Existing Iwi or Māori Partnership Boards

DHB 'partnership boards' were set up around the country to consider the Māori health needs in their region – unfortunately not all DHBs continue to have such a model. Different Māori community profiles are often reflected in the range of membership or representations, including iwi and Māori community. Approaching such a group may be an avenue to developing Māori relationships to share support and advice.

New Partnerships

Te Kahu O Taonui (Tai Tokerau Iwi Chairs Forum) was formed by nine iwi entities in Te Tai Tokerau and has entered into relationship agreements with local councils and with the District Health Board. "We come to the table with a commitment to working in partnership and making a real difference for all in Tai Tokerau to achieve our shared aspirations."[13]

Update Note: The Office for Māori/Crown Relations (Te Arawhiti) has provided Guidelines for Engagement with Maori. While the guidelines focus on the relationships between Crown agencies or Government Departments and Māori, the outline of the engagement strategy can provide an approach for effective relationships with non-government organisations (NGOs) like hospices. https://tearawhiti.govt.nz/te-kahui-hikina-māori-crown-relations/engagement/

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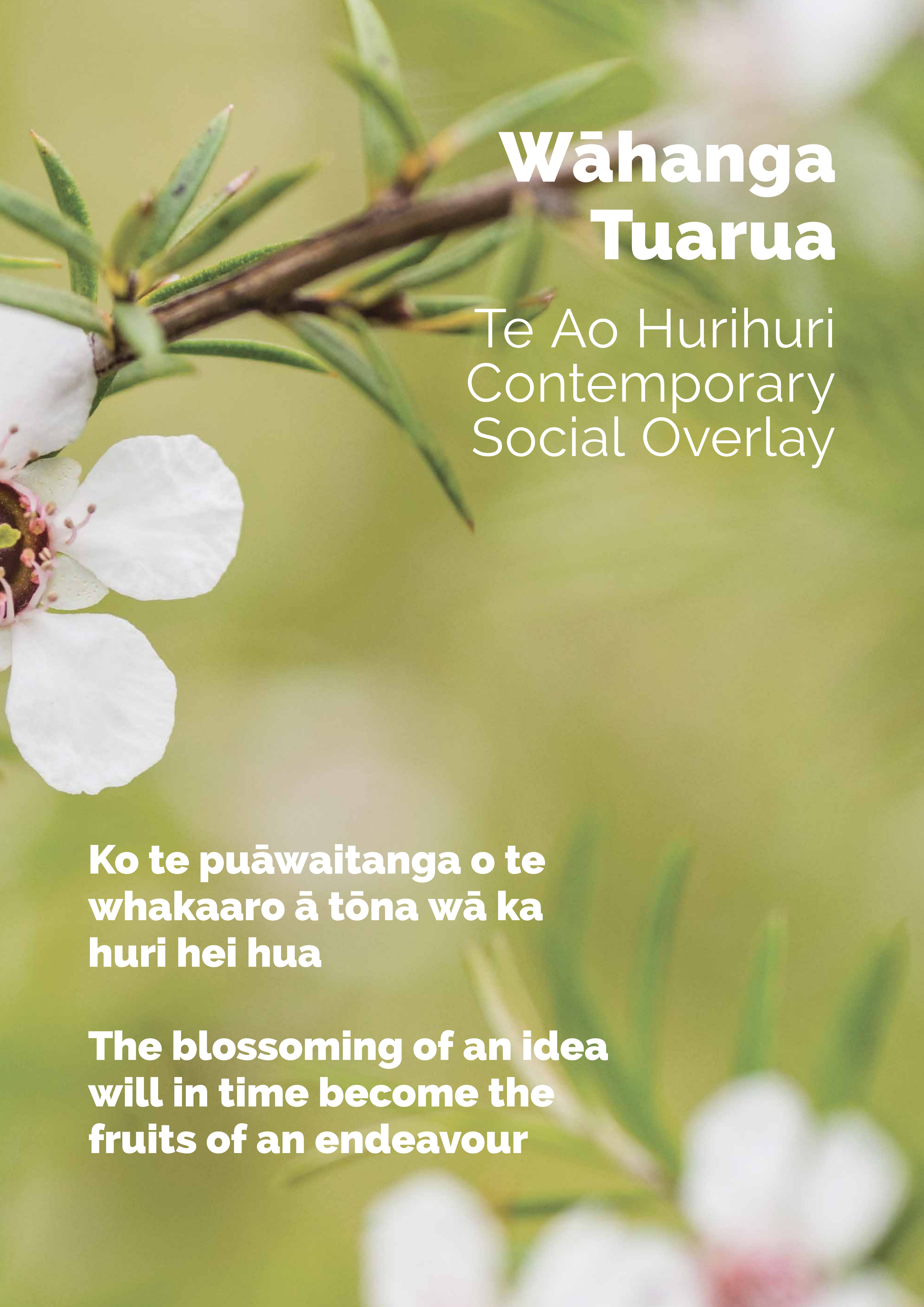
[12] www.marypotter.org.nz 'about us – whetū i te rangi' section

[13] Google 'Te Kahu o Taonui (Northland Collective of Taitokerau Iwi Chairs) and Mahitahi Hauora PHO



Wāhanga Tuarua

Te Ao Hurihuri
Contemporary Social Overlay

Ko te puāwaitanga o te whakaaro ā tōna wā ka huri hei hua

The blossoming of an idea will in time become the fruits of an endeavour

Te Mārama ki tō Tātou Taupori:
Understanding Our Population

Understanding the population of the communities that we serve is an essential and useful start. This should include the ethnic mix of people in your hospice service, and the ethnic demography of the local community. Additionally, hospice services can be informed by recent district and regional Māori population statistics – that is, the numbers, percentage, age and gender, location, characteristics of deprivation and hospital utilisation data. DHBs will usually have up-to-date publications on future projections of changes of Māori population informed by current health status, morbidity and projected survival ages. Building a useful working relationship with the DHB population health team will aid a hospice in understanding the current and emerging needs of the Māori population.

Obtaining information relevant to your community can be derived from many sources. We recommend that hospice administrative data use standard ethnicity data protocols,[14] along with any local DHB-commissioned work on local, district or regional Needs Analysis and obtaining work commissioned by Hospice New Zealand from Professor Heather McLeod. This should highlight current needs and emerging patterns of need by DHB.

Understanding the Māori community in your region will also mean getting to know and understand which iwi and/or hapū have an historical relationship to the area and make up the local communities. This is often expressed as 'mana whenua'. In towns and cities, understanding how the urban Māori communities are organised and where are they are located is important. These communities are often referred to as 'taura here' or 'mātāwaka'. This knowledge will be essential steps on the journey of building partnership relationships (*outlined in Wāhanga Tuatahi*). Māori iwi and groups often feel bombarded with consultation documents and partnership requests. They will have their own pre-existing priorities, so the development of a relationship may need to develop over time, and not work within a constrained time frame. Sometimes the relationship may take an unexpected shape.

Good engagement and relationships with local Māori communities are important partnerships as well as part of the communication channels for hospices. These relationships, as noted above need to include mana whenua (local iwi and hapū) as well as mātāwaka or taura here (including urban Māori community groups and Māori health providers). This relationship is an important means for dispelling myths about hospice (such as being an in-patient-only service or a place to die), and it is a means of gaining support for the patient and whānau. And finally, it is a channel for receiving useful information and views on the hospice service.

A 'Compassionate Communities approach' is another process where hospice services can build relationships that reach out to Māori, either through a targeted approach to Māori communities, or to those Māori people who may be less well connected to their communities (e.g. by working with more generic community health and social service organisations).[15]

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[14] Ministry of Health. (2017). HISO 10001:2017 Ethnicity Data Protocols, Wellington

[15] *Compassionate Communities'* is an approach which is aimed at generating discussion (on death and dying) in different parts of the community, which provides a stronger support to community members who may be dying or grieving. It is viewed as a 'public health' approach that recognises that death is part of life and aims to break down the fear often associated with death and dying. Events of this style are often less formal, group oriented and hold an element of creativity and wonder. This style of information sharing, and exploration may be less confronting and align well with kaupapa Māori approaches.

Te Pāpori Whakauaua: Social Complexity

Research evidence confirms many Māori whānau are highly resilient and draw upon their customs to provide end-of-life care despite their social circumstances. Hospice workers, especially social workers, need to be alert to the potential of high social complexity that may be present for the Māori whānau and how they can support the resilience of whānau to care for their own.

Māori whānau live with disproportionate levels of social complexity – lower income, poorer quality housing and/or inadequate housing, higher number of dependants, more single parent households, and higher rates of unemployment or under-employment. Māori experience more disadvantage than non-Māori (for example, Māori are approximately 2.5 times more likely to be in quintile 10 – the poorest grouping).[16] They may have significant issues and challenges in the wider whānau that create additional complications in respect of managing a terminal illness.

Professor Sir Mason Durie identified the need to recognise 'diverse Māori realities'.[17] This insight relates not only to diversity in Māori cultural participation (e.g. active in te reo and marae activities); it also relates to the socio-economic realities for Māori, and the social dynamics to manage palliative care at home as well as the challenges of navigating our health and social service system.

There has always been a marked preference by Māori whānau to undertake end-of-life care at home. But the social and living circumstances may take a very heavy toll on the whānau supporting care at home. Levels of stress and the impact of loss or grief is more likely to increase when combined with other issues, for example, different patterns of chronic illness, younger age at end-of life, care for other dependents, lower income or benefit incomes or giving up income to provide full time care at home, and housing situations (especially where state housing or social housing is involved). As with all patients, a social and cultural assessment is important. For Māori whānau it can be critical to the overall experience. Other useful linkages include the local community health providers and working with Whānau Ora Navigators.

It is also important to consider that many of the health partners of palliative care patients (e.g. primary care or age residential care) do not have access to social work assessments or counselling services that most hospices now have. Aged Residential Care has not been as attractive to Māori kaumātua in the past in comparison to non-Māori. However, with changing population patterns (*see Graph 1*) and a more customised approach by aged care providers (such as the Whare Tiaki, a kaupapa Māori aged care service offered by the Christchurch Methodist Mission 'Wesley Care'), these patterns are likely to change.[18]

Recent work by Professor Heather McLeod (on ethnicity and projected age of death) also highlights population changes that are emerging and will shape differing needs for Māori in the future.

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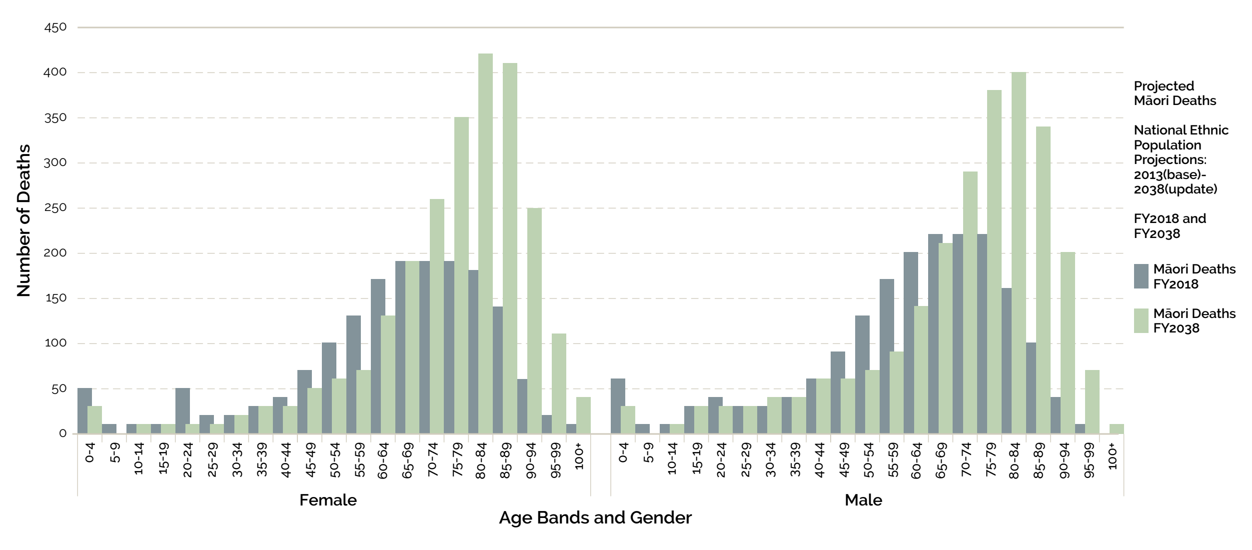
[16] Ministry of Health. (2015). Tatau Kahukura, Māori Health Chart Book 3rd Edition, (Table 4, Neighbourhood deprivation), p11, Wellington, NZ

[17] Durie, Mason. (1998). Whaiora – Māori Health Development. Australia

[18] Brankin, Anna and Beck Eleven. (Dec 18, 2017). Kaumātua Care, A Kaupapa Māori Model, Te Karaka

As depicted in Graph 1[19], by 2038 the kaumātua population will have increased significantly and consequently Māori deaths will increase in number (from 3,000 to 5,000 deaths a year), a 43% increase. This highlights the strategic need to consider the impact on palliative care needs of Māori communities and services, Māori workforce development, and ongoing work with primary care and aged residential care.

Graph 1: Projected Māori Survival 2018 and 2038



While a cultural assessment is part of the expected processes, hospice and palliative care team staff should be mindful that the experience of 'te ao Māori' can vary widely amongst Māori whānau. In other words, caution should be exercised against cultural orthodoxy where an idealised concept of a Māori patient and whānau is imposed on an actual patient and whānau. Nevertheless, the desire to express their own unique cultural identity in the experience of dying, death and grieving may become stronger or may become more urgent at this time. Providing cultural support is another way that hospices can provide quality care to Māori whānau.

Dr Tess Moeke Maxwell and her Te Ārai colleagues have been collecting stories from Ngā Manu Kupu Ai (whānau digital storytellers) and creating 2-3 minute video vignettes about whānau experiences of using their care customs at end-of-life.

Korero Pūrakau, storytelling, is an indigenous Māori approach that allows information, explanation and experiences to be shared with whānau.[20]

The first set of these videos from Ngā Manu Kupu Ai.[21]
https://www.youtube.com/watch?v=G9zXJOnRuEI

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[19] Graph 1– Courtesy of Professor Heather McLeod, prepared for Ministry of Health Palliative Care Panel, 2018

[20] Williams, L., T. Moeke-Maxwell, S. Kothari, S. Pearson, M. Gott, S. Black, W. Hansen. (2015). Is digital storytelling ka pai for New Zealand Māori? Using digital storytelling as a method to explore whānau end-of-life caregiving experiences: a pilot study. BMJ supportive & palliative care, 5(Suppl 1). 23

[21] Ngā Manu Kupu Ai. (2015). (Māori Digital Stories tellers – videos about Whānau Caregiving), produced by Te Ārai, Palliative Care and End-of-Life Research Group, School of Nursing, Faculty of Medicine & Health Sciences, University of Auckland, located on https://www.youtube.com/watch?v=G9zXJOnRuEI

Ngā Whānau Kanorau, Ngā Wheako Kanorau: Diverse Whānau, Diverse Experiences

Urban Māori with palliative care needs may not have enough whānau support leaving them reliant on friends, neighbours or service providers. Rural Māori may experience limited or non-existent local palliative care services. Recognising and then managing the diverse needs of Māori is a critical starting point.

Preferences of care may differ between a patient and their whānau. Some patients prefer to maintain independence by continuing normal life patterns for as long as possible and some may reject offers of help from whānau (often in an effort to protect them from the carer burden of stress and financial difficulties associated with caregiving). Some Māori people prefer to manage their own health requirements (attending appointments, administering medication). Some patients seek to continue to honour their social obligations and contribute to whānau and community, while others will retreat from these obligations seeking the privacy and intimacy of whānau.

Autonomy and self-determination are sometimes at odds with *whanaungatanga* (relationships, connections, interdependence). See discussion Āpitihanga 2 (Appendix 2).

Recommendations

Hospices develop care plans that are informed by and record the support needs and preferences of care of Māori patients and whānau.

Care should be taken to respectfully note differences between patients and whānau and describe how the differences are resolved where possible or managed when not resolved.

Care plans should be kept up to date over the course of the palliative care journey.

Te Tāmitanga Ā-Whakapapa: Inter-Generational Trauma

This term is currently used in discussions to refer to the ongoing impact of trauma from one generation to the next, or to multiple generations. The transmission of traumatic effects may have long-lasting effects on the behaviour of individuals or whānau, or they may arise and reoccur at times of stress.

Examples of trauma that can be transmitted from one generation to the next, may include;

- Impact of colonisation including loss of land and resources, and the undermining of the social and cultural 'resources needed to rear children and protect whānau.
- Government policy and legislative changes that may have a significant impact on Māori: examples include adoption secrecy, the removal of children into the care of the state and the actual care as a state ward, or court decisions on sentencing, especially imprisonment.
- Abuse – physical, mental and sexual (as above, this may have occurred in a state care setting).
- Intractable intergenerational poverty occurring through major economic changes.
- Mental health trauma (including war-time experiences).
- Multiple death experiences (compounding loss and grief).

This list is but a reminder to recognise that such impacts may generate complex grief reactions for Māori people and their whānau. It may also generate conflicting or difficult decision-making processes for the patient and whānau.

> *Kaimahi Māori (the Māori hospice workers group) considered the issue of inter-generational trauma at the 2018 network hui. Their views were:*
>
> *A number of approaches have been developed (through counselling, mental health, rongoā and kaupapa Māori services) to mitigate such impacts and to re-integrate cultural, spiritual and creative aspects in a person.*
>
> *These approaches can be particularly effective healing approaches for spiritual pain generated as a result of inter-generational trauma.*
>
> **Kaimahi Hui – Te Tii, Northland, 2018**

Ngā Mariu Whakapā a te Māori: Māori Preferences for Communication

Research has highlighted how critical it is to have culturally competent communication with Māori patients and their whānau to assist them with navigating the health system. Health literacy issues and complex written information can easily complicate the process of making decisions and choosing options for appropriate care[22]. While these issues are not exclusive to Māori, there are a number of factors, outlined in this document, that may be usefully included in the communication process.

Whānau inclusion in discussions from the beginning of the patient interaction with the hospice service has been identified by Māori in the literature. Effective, compassionate, communication between professionals and whānau and patients, is critical.[23]

Māori whānau will, in general, prefer face-to-face communications, especially in the initial stages when relationships are being developed. Over time they may become more comfortable with other forms of communication, including telecommunications, audio-visual, text and written forms of communication.

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[22] Ministry of Health. (2014). Wellington

[23] Ministry of Health. (2014). Wellington

Because of the diversity, size and sometimes complexity of Māori whānau, palliative care multi or interdisciplinary teams should be mindful that Māori whānau may need additional communication events or that whānau may request repeat communications or may request additional time to consider the advice and information that they are being provided.

We assert that it is indeed usually feasible to provide extra time for decisions, or even for the patient or whānau to consult with whānau who are not present or with advisors or elders. Permission may be gained from whānau to allow hospice staff to also consult wider whānau advisors or elders to support having appropriate care in place. Providing such options can be respectful of cultural processes and it can help to demonstrate the care partnership. If there are real constraints on time frames for decisions, it is good to be explicit about why and how much time there is practically.

Māori preferences for communication will depend on the resources of each whānau, and palliative care interdisciplinary teams should be alert to changing requirements or preferences.

While 'te reo Māori' is valued by most whānau, competency in te reo is not universal. However, correct pronunciation of Māori is expected. Research has highlighted the importance of pronouncing a person's name as something that is highly valued.[24]

Developing the communication skills and critical reflections skills of hospice staff, including those around group discussions, will contribute to ongoing effective communication with Māori patients and whānau. The multi-disciplinary team approach and use of Māori staff, can provide more effective communication processes with Māori patients and their whānau.

Kaimahi Māori[25] *considered the issue of Māori communication preferences at the 2018 hui:*

A key issue has been the need to 'pace' the discussion.

Ata haere! Slow down.

Avoid overwhelming the patient and whānau, take care with terminology and technical (medical) jargon, use a 'less formal' approach if possible and have the initial discussion face-to-face (preferably with the whānau present).

If more time is needed, then explain what other matters need to be discussed and then agree a plan to work through the discussions.

Kaimahi Hui – Te Tii, Northland, 2018

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[24] Mason, K. and T. Moeke-Maxwell, (2018). Te Ārai, Palliative Care and End-of-Life Research Group, School of Nursing, Faculty of Medicine & Health Science, University of Auckland). Māori and Palliative Care, Literature Review Report for Te Ohu Rata o Aotearoa

[25] Māori hospice workers network group

Ngā Pārongo: Information

Palliative care generally works well for whānau when they have a good understanding of the health system, good access to statutory resources (carer benefits, home help, equipment), the information they want or need to know (regarding illness, prognosis and treatment) and services that are flexible and able to adjust to the diverse needs of whānau.

Recommendations

Hospices develop specific information packs:

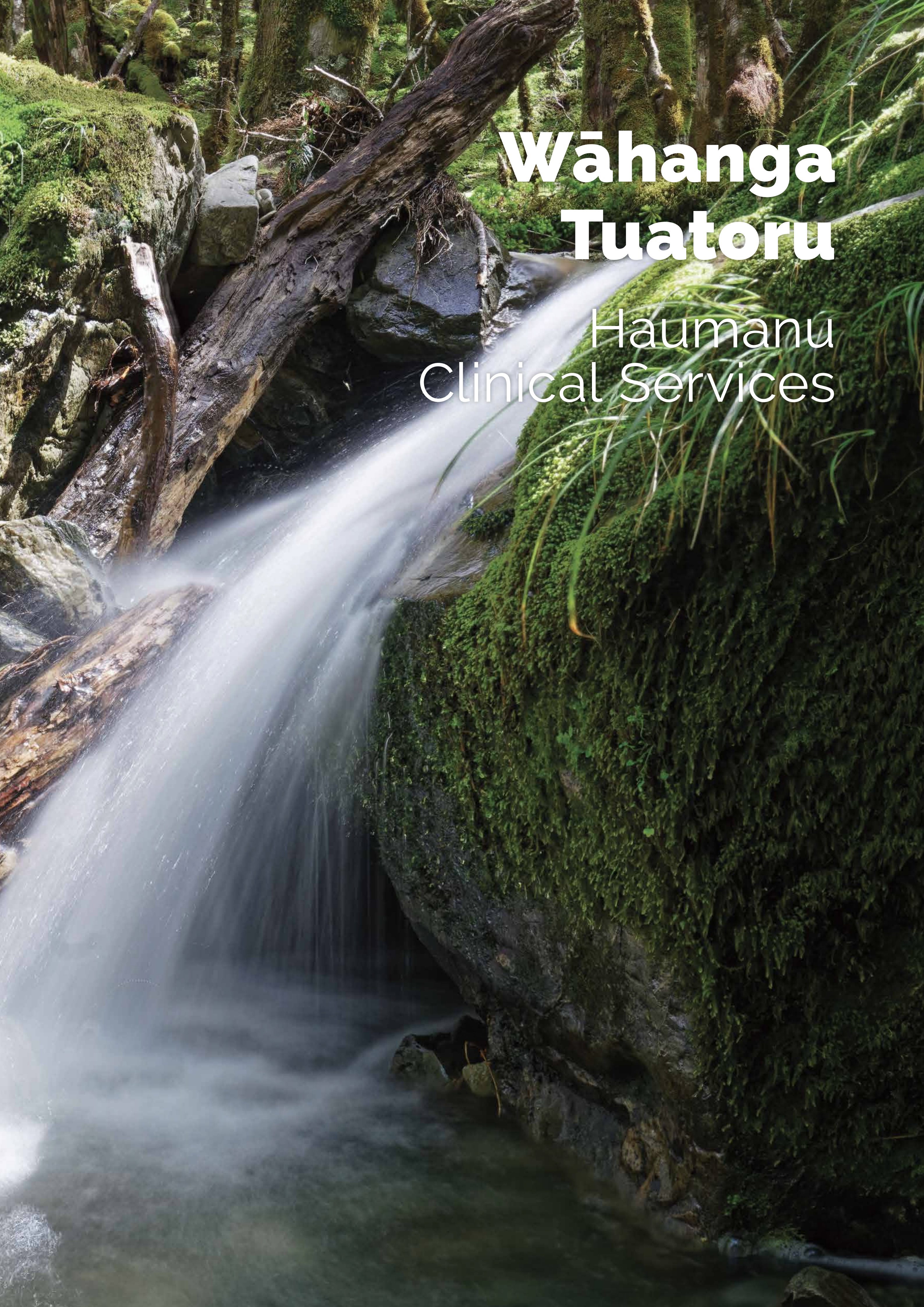
- designed and tested with Māori patients and whānau
- delivered by hospice staff describing palliative care services
- introduce key concepts for the palliative care journey
- useful up to date contact details, assistance or entitlements, and how to access these.
- Further information or vignettes drawn from real case studies is likely helpful in resources conversations within whānau and with hospice staff about the palliative care journey and cultural customs at the end-of-life.

Mōku anō ēnei rā te rā ka hekeheke;
he rākau ka hinga ki te mano wai

Let these few days with the
declining sun, be for me; a tree
falling into deep running water

Wāhanga Tuatoru

Haumanu Clinical Services



Te Haumaru Ā-Ahurea me te Mātanga Ā-Ahurea:
Cultural Safety and Cultural Competence

Both concepts of '*cultural safety*' and '*cultural competence*' are about the relationship between the helper and the person(s) being helped.

Cultural safety is where the recipients of care, that is, the patient and their whānau, determine cultural safety – that is, how they experience the care and the approaches of the service.

Communicating information in ways that are accessible, understandable and appropriate will assist the process. *Hearing* what matters to the patient and their whānau, will determine whether the service can claim to be culturally safe and is able to manage the individual and collective preferences and needs of Māori patients and whānau.

The work of Irihāpeti Ramsden on cultural safety and cultural competency is now a much broader concept than when it first emerged in nursing education in Aotearoa.

Cultural competence is focused on the health worker – on their capacity to improve health status, or care, by integrating cultural behaviour into the clinical context.[26]

Research has highlighted how critical it is to have culturally competent communication with Māori patients and their whānau to assist them with the complex range of information and options in palliative care.[27]

A useful description of cultural competence

The ability of individuals to establish effective interpersonal and working relationships that supersede cultural differences by recognizing the importance of social and cultural influences on patients, considering how these factors interact and devising interventions that take these issues into account.[28]

It is worth noting that communication training for many health professionals is a relatively recent innovation. Communication between colleagues and members of the interdisciplinary team is also critical in conveying important information.

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[26] Durie, Professor Mason, (2001). "Cultural Competence and Medical Practice in New Zealand", Paper delivered to the Australian and New Zealand Boards and Councils Conference (p2).

[27] Ministry of Health. (2014). Palliative Care and Māori from a Health Literacy Perspective. Wellington: Ministry of Health

[28] Beach, M. C., E. G. Price, T. L. Gary, K. A. Robinson, A. Gozu, A. Palacio, C. Smarth, M. W. Jenckes, C. Feuerstein, E. B. Bass, N. R. Powe and L. A. Cooper. (2005). Cultural competence: A systematic review of health care provider educational interventions. Medical Care 43 (4): 356 – 373 (Discussion section)

A Reflection on cultural competency and cultural safety

A training approach which highlights the need for 'critical self-reflection' is considered as an effective way to increase cultural competency:

by critical self-reflection, we do not mean a singular focus on the self, but a stepping back to understand one's own assumptions, biases, and values, and a shifting of one's gaze from self to others and conditions of injustice in the world.[29]

Training in the concept of cultural safety is often confronting and challenging for health professionals, especially if their contact or interaction with 'te ao Māori' has been very limited. Hospices have a key role in education not only of their own staff but those in the wider health sector (including Māori providers).

Update Notes: Released jointly by the New Zealand Medical Council, in partnership with Te Ohu Rata O Aotearoa (Te ORA), Statement on cultural safety and He Ara Hauora Māori: A Pathway to Māori Health Equity November 2019.

Also Released in November 2019 by the New Zealand Health Quality and Safety Commission, video training resources for the health sector on Implicit Bias – see Commission website: 'patient safety week 2019 resources' – a different access is required for Clinical (Medical or Nursing) Education points.

Kaimahi Hui 2018 *considered the issue of cultural safety for Māori and outlined a full spectrum of training and support they felt would be useful for their colleagues and hospice staff. In addition to training in critical reflection, they felt training could include:*

- *involvement of local Māori communities with the hospice, especially kaumātua (employed or contracted – if volunteers, ensure their time is respected and valued);*
- *understanding Treaty and social/colonial impacts on Māori whānau*
- *using Māori staff well*
- *understanding Māori cultural forms (powhiri, waiata, te reo) and*
- *good listening skills.*

Bringing in people who have expertise is a way of ensuring that Māori staff are not burdened with any negative emotional response of their colleagues.

Kaimahi Hui – Te Tii, Northland, 2018

Recommendation

Hospices develop staff training (for all health professionals) on cultural safety and cultural competency with supporting resources that describe Māori diversity, Māori preferences and hospice resources, that will meet the needs of Māori patients and whānau.

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[29] Kumagai, A. & M. Lypson. (2009). Beyond cultural competence: Critical consciousness, social justice and multicultural education. Academic Medicine, 84 (6): 782 – 787 (p3)

Ngā Whakapātanga Haumanu: Clinical Communication

Hospice and palliative care practice recognises the importance of good communication with patients and their families – as a means of understanding:

- what matters to patients (and whānau) at the end-of-life
- what is happening and how that might change
- what are the options now, and in the future

The discussions prior to referrals to hospices are just as important as those occurring once someone is in a hospice service. A heightened emotional state (and these discussions invariably generate anxiety and high emotional states) can mean that people simply don't hear the message. Other issues are well recognised and documented in palliative care literature, including the potential deterioration of intellectual capacity.

The negative impact of poor communication (including those discussions outside the hospice service at the beginning of the clinical interaction), can affect the whole palliative care journey for the patient and whānau. The reverse is also valid – good communication at this stage is valued and well-remembered by both patients and whānau and leads to a quality experience that has a real impact on healing grief.

Hospice services need good working partnerships and relationships with other health services, including Māori health providers. Promoting examples of good communication, as well as providing training and support services (offered by most hospices) supports these relationships. Good clinical communication between colleagues (both internally and externally) is also critical. Often, the communication between the hospice and colleagues (across organisations, other parts of the sector and professional disciplines) can make a significant difference in the care leading up to and including the end-of-life.

Another study noted that whānau frequently had members who were accessing the internet or social media to find information to meet their needs. Hospices are aware information needs change as the illness progresses and the clinical situation or needs evolve. Being able to talk to whānau about what is useful and relevant in their situation or not, would be helpful for their journey.[30]

Information targeted for Māori is enhanced by improved information (written, visual, video and social media) that can be used by hospices in discussion with Māori patients and whānau. Consideration of this could be a national project, so long as resources can be adapted locally and are developed by those with cultural expertise. Written material and social media communication can support culturally effective communication, including with whānau groups.

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[30] Ministry of Health, (2014). Palliative Care and Māori from a Health Literacy Perspective. Wellington: Ministry of Health

Targeted communication resources:

Ngā Manu Kupu Ai (Māori digital storytellers) are documented in 2 to 3 minute videos talking about whānau experiences at the end-of-life. Based on research by Dr Tess Moeke-Maxwell and her colleagues at Te Ārai, Palliative Care and End-of-Life Research Group, School of Nursing, Faculty of Medicine & Health Science, University of Auckland.[31] ***https://www.youtube.com/watch?v=G9zXJOnRuEI***

Advance Care Planning video narratives launched 2019 by NZ Health Quality & Safety Commission.[32] ***www.myacp.org.nz***

A further study highlighted the importance of peer communications or 'word of mouth' within Māori communities to pass on views about the quality of the service, including cultural safety of the service. Using appropriate opportunities to present such views to both a Māori audience and to hospice staff may be an approach that could be developed.[33]

Many hospices use the approach of asking the whānau to identify one person with whom all discussions will take place. This approach was introduced to prevent confused multiple messages being passed on to whānau by hospice staff. This process however can be burdensome on the key member of the whānau who has this role. Hospice staff need to regularly check and be prepared to change processes so the 'weight' of communication with the whānau can be shared amongst members. Other whānau members may have different whānau responsibilities or skills and may also need to be identified for specific areas of care decisions or information.[34] This may require alternative approaches such as repeat or duplicate discussions, or written summaries of discussions.

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[31] Ngā Manu Kupu Ai (Māori Digital Storytellers) (2015) – videos about whānau caregiving, produced by Te Ārai, Palliative Care and End-of-Life Research Group, School of Nursing, Faculty of Medicine & Health Science, University of Auckland, Auckland retrieved March 2019 https://www.youtube.com/watch?v=G9zXJOnRuEI

[32] New Zealand Health Quality & Safety Commission. (2019). Advance Care Planning video narratives, www.myacp.org.nz

[33] Slater, Tania, Anna Matheson, Cheryl Davies, Ria Earp, Kate Gellatly, Maureen Holdaway, Lis Ellison-Loschmann. (2017). Exploring Māori cancer patients', their families', community and hospice views of hospice care, International Journal of Palliative Nursing, Vol 21, No 9, p 439 – 445

[34] Ministry of Health, (2014). Palliative Care and Māori from a Health Literacy Perspective. Wellington

Rongoā Māori

Traditional Māori healing or Rongoā Māori has seen a revival over recent decades (having been legally suppressed for generations). This has resulted in the growth of a small number of Māori providers (with an even smaller number receiving contracts). Traditional Māori healing is firmly fixed in a Māori cultural and spiritual framework – it may include any combination of karakia (prayer), mirimiri (therapeutic massage), romiromi (deep massage), rongoā rākau (healing plants) and mauri mahi (energy and/or sound or aural work).

Rongoā rākau sits outside the pharmaceutical regulations, however such approaches should at minimum be compared with herbal remedies. The strong connection to Māori cultural concepts provides comfort and a spiritual link beyond the healing or symptom management properties of rongoā rākau remedies alone.

Rongoā Māori is informed by a body of knowledge that has as its core the enhancement of Māori wellbeing. In this way, Rongoā Māori differs from a Western medical paradigm, whose focus is principally the absence of health and well-being and treatments/interventions to a return to a state of health.[35]

Developing relationships with rongoā healers or providers is a useful approach for a hospice to develop both for referrals or for increasing knowledge. The clinics tend to be small and/or associated with kaupapa Māori providers. Some whānau practice Rongoā Māori at home for whānau first aid and for general wellbeing. Contracted providers can be located through the following site; ***https://www.health.govt.nz/our-work/populations/Māori-health/rongoā-Māori-traditional-Māori-healing***.

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[35] Ministry of Health, (2014). Palliative Care and Māori from a Health Literacy Perspective. Wellington

It is helpful to ask the patient and whānau whether they are using any traditional healing or complementary approaches, including rongoā rākau. Remembering that rongoā rākau was suppressed for generations[36] and that it still elicits a sceptical response from many clinicians, we would suggest that a careful tactful approach is used or that Māori staff ask this question.

Best Practice Advocacy Centre (bpacnz) which targets primary care, set up a reference in 2008 for Rongoā Māori which provides a description of the plant name, the processes and what issue is being treated. This provides relevant information to clinicians to assist in their understanding on how various plant remedies are used and for what purpose. Once clinicians are aware of the use of rongoā rākau, they can then make an assessment of the potential impact of other pharmaceuticals and interventions. It is possible that rongoā rākau may contain active ingredients. However, as long as pharmaceuticals are not deliberately added, no restrictions apply to the use of these plants.[37]

Further research describing the use of rongoā rākau in palliative care is needed. Guidelines into rongoā research were published in 2018 by researchers, Doctors Glenis Mark, Marion Johnson and Amohia Boulton, to assist rongoā practioners working with health researchers on their practice and to assist researchers. The document can be found on Whakaue Research Centre website.[38] The Hospice Kaimahi Hui 2018 workshop recommended that as a national project should undertake further work on rongoā rākau in palliative care.[39]

Recommendation

Further research is encouraged and developed regarding the use of rongoā rākau and rongoā practice in palliative care, noting the guidelines published by Whakaue Research Centre on their website.

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[36] Tohunga Suppression Act 1907

[37] Best Practice Advocacy Centre (bpacnz), (May 2008), Demystifying Rongoā Māori in Best Practice Journal, Issue 13, pgs 32–36, https://bpac.org.nz/BPJ/2008/May/docs/bpj13_rongoā_pages_32-36.pdf

[38] Mark, Glenis, Marion Johnson, Amohia Boulton, (2018). Cultural, Ethical, Research, Legal & Scientific (CERLS) Issues of Rongoā Māori Research, Whakaue Research Centre, Whanganui.

[39] The hui specifically recommended Donna Kerridge, rongoā healer, registered member of the NZ Association of Medical Herbalists http://www.nzamh.org.nz/donna-kerridge

Te Manaaki Haumanu: Clinical Care

The accepted practice for hospice palliative care includes; assessment with effective inter-disciplinary processes; a care plan with goals developed with patient and whānau; clinical care to manage symptoms, pain and anxiety; good communication with whānau and carers about what to expect; managing the transition between other health partners and settings (e.g. primary, hospital, community and aged care); and a holistic approach that includes spiritual and bereavement care.

We have articulated the importance of; a strong commitment to a whānau focus, to reflective practice that aims to provide a culturally safe service, and to good communication processes with patient and whānau as well as between members of the team. These approaches are recognised as effective when the team operates in a supported environment.

Clinical care is enhanced when the accepted practice of ensuring all professional staff are registered with their respective professional body, understand the raft of legal and policy decisions that may apply to them, and that clinical staff are supported and continue to participate in appropriate training.

Assessments

A holistic assessment includes a comprehensive physical, psychological, social, spiritual and cultural assessment informed by patients and their whānau. The assessments, involving the interdisciplinary team, should provide a responsive personalised care plan that is amenable to change or review as the patient journey unfolds. The plan is critical for co-ordinated timely care service for Māori patients and their whānau.

Widespread use of the model *Te Whare Tapu Whā* within hospice services also serves to underscore the holistic elements of an assessment and the development of a customised care plan. Other Māori models in use include *Te Wheke* (see resources for the Wairuatanga module within the Foundations of Spiritual Care) and *Te Pae Māhutonga*.

Helping the patient and whānau understand the prognosis and how the changes could be clinically managed will assist the whānau to clarify their options. It is important that the whānau and the patient, identify what is important to them and how those options best fit.

Psychological support for Māori patients and their whānau could include addressing issues such as anxiety or depression, and, may specifically include addressing the psychological concerns or experiences for whānau. The intention is to provide psychological and other support for whānau so that they can be present, engaged and supportive of their family member.

Recommendations

Hospices specifically enquire and engage with Māori patients and whānau about their intentions, preferences or needs in respect to tikanga Māori. This should be recorded in the care plan and should be visible to the patient and whānau.

Hospices specifically discuss the opportunity to support cultural practices.

Care Practices

The majority of palliative care needs of the dying are managed and met by whānau / family caregivers.[40] The cultural safety of services (and interventions) still applies regardless of where that care is taking place. This document highlights the care of Māori patients and whānau in the home, the inpatient unit and with other organisations (including aged-care or hospital facilities).

Caregiving practices by Māori caregivers can incorporate a range of traditional Māori cultural customs. Furthermore, cultural practices can help strengthen whānau caregivers by increasing their resilience.[41]

Māori whānau will often prefer to provide care themselves. If the offer of support and additional resources is made in a way which is seen as supporting them as the central, albeit, unpaid and often informal care resource, then many whānau may accept and receive additional support services. This can include offers of physical resources, specific care services or additional or intermittent care services such as respite care either in the home or in-patient care.

Support staff may need to invest significant time and resource to support the capability and wellbeing of some carers. This is especially important when the whānau member wants to continue to be cared for at home and that care is full-time (rather than going into an aged residential care setting, for example). Going into an alternative facility may also mean losing accommodation (social housing) for several generations sharing the home.

It may be that whānau want to continue some care roles, even if the patient is admitted to an in-patient unit. This should be supported as far as possible. Some hospices have developed 'Tikanga' policies, often modified from those developed by local Māori hospital teams. These largely (but not exclusively) apply to inpatient care – one such example is the policy developed by Capital Coast DHB (sourced from other DHBs, especially the early work by Waitemata DHB), so check with your local DHB ***https://www.ccdhb.org.nz/our-services/a-to-z-of-our-services/maori-health/#tikanga-maori-a-guide-for-healthcare-workers***.

Recommendations

Hospices care plans are informed by and record the support needs and preferences of care of Māori patients and whānau. Care should be taken to respectfully note differences between patients and whānau and describe how the differences are resolved where possible, or managed when not resolved. This needs to be kept up to date over the course of the palliative care journey.

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[40] Gott, M., J. Wiles, A Rolleston, T. Teh, T. Moeke – Maxwell, N. Kerse, (2017). End-of-Life Preferences amongst people of an advanced age, LiLACS NZ, BMC Palliative Care 16(1), 19

[41] Moeke-Maxwell T., L. W. Nikora, & N. Te Awekotuktu, (2014). End-of-life care and Māori Whānau resilience, Mai Journal, 3(2), 140–152

Cultural Care

Relationships with Māori communities and Māori providers provide some of the links that could assist hospices to meet cultural needs, especially when the capacity of internal staff is stretched. Since cultural views are woven throughout this document, this section only highlights the importance of being aware of the powerful pull of this connection at the end-of-life.

It is worth repeating – *Whanau are at the centre of the Maori world* – a Māori model of palliative care appropriately acknowledges and works with the centrality of whānau.

Māori providers may offer enhanced community services and cultural links which might not otherwise be available through general practice or hospice services. For Māori speakers, the desire to hear and speak in te reo Māori is often stronger at the end-of-life.

One uniquely Māori issue may be an assistance request to give advice or link to someone who can advise on Māori land (which needs to be managed through the Māori Land Court) or Māori taonga (treasures) bequests. Simple owner and block searches can be done online (Ministry of Justice: Māori Land Online). This may also generate mixed emotions for people.

Respite Care

Respite care is an important service to assist whānau to maintain their care-giving role at home – particularly if the care-giving falls on a limited group or a single person. Respite care will depend on the facilities (or arrangements) of each hospice and has the additional benefit of providing an opportunity to review care arrangements, symptom management or whānau support.

An alternative to in-patient respite care is ‘home respite care’ which then allows the carer to attend to other tasks outside the home. Different approaches have been adopted by hospices and may involve any combination of; referral to a DHB funded support services, volunteers in the home, day clinics, and day programmes with creative art/music activities.

Recommendations

That given the strong Māori preference for care to remain in the home, hospices evaluate and assess their data and their day and community programmes to identify what type of services are being accessed by Māori whānau and what changes might be required.

As assessment, audit and patient or whānau feedback processes have been largely developed with a mainstream focus, that:

- alternative consumer-feedback, or quality audit processes be developed and trialled to capture targeted Māori views of hospice service
- a cultural audit tool be developed to assess fully the hospice service to identify gaps, service change and training needed to improve the hospice service.

End-of-Life Care

'Te Ara Whakapiri – Principles and Guidance for the Last Days of Life' is the New Zealand guidelines for quality care in the last days of life, and serves as a foundation document for all policies and procedures concerned with care at the end-of-life and for all education initiatives.

Along with other providers in their local DHB region, hospices have created and adopted tools and templates that are consistent with *Te Ara Whakapiri*.

The first step is the recognition that the person is dying.

Based on previous discussions (where prior discussions have taken place) with the person and their whānau and carers, the document outlines the need to reassess physical needs, review current management and anticipatory medication, identify the preferred place for care at the end-of-life, identify and remedy communication barriers, consider the person's awareness of their changing condition, as well as the awareness of the whānau and finally, identify cultural and spiritual needs at the end-of-life.

If a person is at home, it is really important that a discussion with the whānau and carers is undertaken in advance and they have contact details should circumstances change and a good understanding of the available supports.

The end-of-life support in the home is another critical service for family and carers. The arrangements within DHBs to fund additional support (e.g. presence of a night nurse or caregiver in the home) does differ across the country – it may require the hospice to advocate on behalf of the whānau. This type of care support can ensure that the care continues in the home when that is the patient and whānau wish. It can assist to lessen emotional and physical exhaustion that can accumulate.

Where the dying is taking place in a health facility (hospital, aged care facility or in-patient unit) it is common practice for Māori to have whānau (including children) present. Some whānau members will expect to stay with the person through to the end-of-life, including night. While this is a common hospice activity, staff may find the larger groups of people (and children) challenging – internal policies and practices will assist in managing larger family numbers. Whānau will expect that the room has been blessed before admission and after a death.

Ngā Hiahia Motuhake: Special Care Needs

Within the Māori communities of Aotearoa, there are also those with special needs – this section is intended to highlight issues, not provide a definitive guide.

Rural Communities

Providing palliative care to patients and whānau in Māori rural areas communities face the same challenges as other rural health services; for example – remote distances, lack of locum and back-up services, and workforce pressures. They also experience some unique challenges.

Māori are recognised as one of the most rapidly urbanised indigenous peoples globally.[42] This has created a situation where poor rural Māori communities have even fewer resources to call on (including public health infrastructure) than their urban cousins. Family members are more likely to be dispersed, roading, communications and other public health infrastructure may be missing or less actively maintained and incomes lower, with housing in a poor state.

The need for in-patient care at a hospital or hospice (monitored treatment, assessment or continued supervised care) may become an issue for Māori patients and whānau requiring a more complex decision-making discussion and links with whānau members who live in the more urban centres. How the hospice communicates and supports health workers in the rural areas becomes a critical issue.

Some communities have experienced a decline in their capacity to fulfil the *ahi-kaa* roles of maintaining the cultural strength of the home marae. The ability to host tangihanga may be a real concern to a rural family or a returning 'urban' whānau. It may be a real challenge to care for returning whānau members.

Models and approaches for appropriate palliative care in rural communities require innovation and high commitment. Liaison with and between hospices providing services to poor rural Māori communities, is one process to highlight how innovation and support can be shared.

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[42] Kukutai, T. (2011). Māori demography in Aotearoa New Zealand 50 years on, New Zealand Population Review, V 37, p 45-64

Prisoner Health

The palliative care health needs of prisoners have been raised as a particular issue facing Māori because Māori have an alarmingly high incarceration rate (in 2014, Māori males were 51% of the prison population, i.e. about 4,500, and Māori females were 63% of the female prison population).[43]

Internationally, hospice and/or palliative care for prisoners is seen as a humanitarian health issue. In New Zealand, it is also seen as a Māori health issue.

Dr Julia Carr outlines the impact of the prison environment on the mental, physical and emotional health of Māori prisoners. She 'pulls no punches' in describing the health impact of imprisonment on Māori prisoners where crime and punishment in Aotearoa is based on a paradigm of colonial Britain and therefore serves to reinforce the dominant culture's structural power imbalances. Dr Carr's 2007 chapter is in *Hauora: Māori Standards of Health IV, A Study of the Years 2000 – 2005*.[44]

Understanding whether your hospice region has prisons or correctional institutions in its region and how health care in the prisons is provided, is the first step in understanding their healthcare arrangements. Knowing the health services and assessing the palliative care need, may provide a critical link with the institutions.

While there is no documented review of prisoner families, it is worth noting that the impact of imprisonment also flows through to the prisoner's whānau, who frequently experience a high degree of disadvantage as a result.

Caring for Carers

Identifying aspects that were working well for Māori patients and whānau, Johnston Taylor[45] identified the following positive experience for Māori in hospice service care:

- respite care easing the strain on whānau carers
- access to equipment and information pertaining to patient care
- bereavement support
- spiritual care, and
- compassionate staff.

Slater[46], in a study of Māori cancer patients, identified findings consistent with Johnston Taylor et al, and added:

- continuity of care
- after hours support
- hospice inpatient units being responsive to whānau needs (beds, kitchen facilities)
- whānau feeling included and supported
- good communication, and
- assistance to apply for benefits and arrange funerals.

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[43] Corrections New Zealand. (2016). Working with Māori video, www.corrections.govt.nz

[44] Carr, Julia. (2007). Prisoner Health, Chapter 15 (p 221-224), in Hauora: Māori Standards of Health IV. A study of the years 2000-2005. Robson B, Harris R. (eds). Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare, Otago University.

[45] Johnstone Taylor, Elizabeth. Shirley Simmonds, Ria Earp, Puhiwahine Tibble. (2014). Māori perspectives on hospice care, in Diversity and Equality in Health and Care, 11: p 61–70

[46] Slater, Tania, Anna Matheson, Cheryl Davies, Ria Earp, Kate Gellatly, Maureen Holdaway, Lis Ellison-Loschmann. (2017). Exploring Māori cancer patients', their families', community and hospice views of hospice care, International Journal of Palliative Nursing, Vol 21, No 9, p 439–445

Most hospice service evaluations do not analyse the responses at the level of detail that will capture the experience of Māori patients and their whānau. Participation in day service programmes similarly do not usually record experiences at this detail-level either. So, understanding the participation of Māori or support of whānau carers is likely being assumed.

Not all hospices have all of the components identified in the research. Each hospice would need to review how these components are expressed (or not) in the service and assess what level of participation by Māori patients and whānau occurs (as a first step). There is opportunity to tailor programmes specifically to cater for Māori patients, or link Māori patients and whānau to Māori targeted programmes (e.g. raranga or weaving, other Māori arts).

New initiatives, especially those specifically targeting carers and carer support, are often based on the implementation of similar or innovative ideas from English-speaking 'like-minded' nations overseas (e.g. U.K., Australia, Canada, U.S.A). Such programmes should be reviewed to assess whether these initiatives are being accessed by Māori patients and whānau and how the participation in such programmes are being experienced by Māori.

Recommendation

That programmes and initiatives that are intended to support caregivers be monitored, reviewed and assessed, to identify whether Māori patients and whānau are accessing such programmes and how they are being viewed by Māori.

Tāngata whaikaha – Māori with a disability

Whāia te Ao Mārama: the Māori Disability Action Plan, provided a new term for Māori with a disability – *tāngata whaikaha*. It also highlighted key data from the Statistics NZ 2013 Disability survey;[47]

- 26% of all Māori identified as someone with a disability.
- just over half of adult *tāngata whaikaha* are in the workforce.
- 4 out of 10 *tāngata whaikaha* have no formal educational qualifications.

In considering the Disability Support Services (DSS), the Disability Action Plan noted that:

- 'Supported Living', which enabled *tāngata whaikaha* to choose to live in the community, had the greatest increase between 2014 and 2016.
- the number of Māori clients allocated Ministry-funded disability supports increased by 18 percent between 2013 and 2016.
- of those people receiving DSS support who identified as Māori (5,920) around 50% were aged under 23 years.
- *Tāngata whaikaha* seek services that allow them to live with choices without being 'labelled', to participate in their community and to participate in *te ao Māori*.[48]

The Action Plan highlights the reason that a Care Plan for any *tāngata whaikaha* who may be referred for hospice palliative care, requires an approach that considers the living circumstances (such as a community shared home), the impact (and potential deterioration) of the disability, and how a Māori cultural view is part of this person's life.

Most Māori disabled people identify as Māori first. The importance of their cultural identity, which encompasses language, whānau, cultural principles, practices and linkages to the land through genealogy, is paramount to how they live their day to day lives in both Te Ao Māori and Te Ao Pākehā.[49]

This extract from Whāia te Ao Mārama focuses on those who are living with their disability – *tāngata whaikaha*. It is not intended to cover the circumstances where a person's body deteriorates with the life-limiting illness, thus creating a disability that is a new experience for the person and the whānau. It is, of course, important to recognise that for these circumstances, the issues outlined above may also apply, noting also that the changing nature of some illnesses will require special care. The role of the allied health team (psycho-social and therapist teams) will be critical in either circumstance.

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[47] Ministry of Health 2018, p4

[48] Ministry of Health 2018, p1–6

[49] Ministry of Health 2018, p2

Sexual orientation, sexuality and intimacy

Sexuality continues to be a challenging issue for palliative care clinicians and service providers. It remains an area that patients may find more difficult to discuss with health professionals. Reflective practice (and training), as outlined in the section on cultural safety, is relevant to discussions about sexuality and the issues that may be facing the person and their whānau. Reflective practice training in this context, is intended to question personal reactions, values, beliefs and attitudes and the impact on the communication and practice of the clinical team.

Personal views of those on the clinical team influence how they relate to those whose sexuality and/or whānau relationships are gay or lesbian or heterosexual. Understanding what matters to the person and whānau receiving the service and how that needs to be built into the care for that person can be more easily articulated if there is a perceived openness and acceptance of this most fundamental personal aspect. And for the sake of clarity, this is fundamental to Māori too.

Te Wairuatanga: Spirituality

Hospices currently run the 'Foundations of Spiritual Care' and we encourage hospices to maintain and continue the modules. The Wairuatanga module is designed to assist hospice staff to understand more about Māori cultural views and the basis for Māori spirituality at a very basic level. Being aware and respectful of cultural traditions of indigenous peoples, must include their religious or spiritual nature.[50]

Māori who interact more intensely with 'te ao Māori' will likely seek support from within their own communities or wider whānau, for example, for *karakia* (prayers, incantations, chants) and, *waiata* (songs) and *hīmene* (hymns). Many Māori who have not had much contact with the Māori world (especially in the urban areas), or may not be actively religious, may find greater comfort from more 'traditional Māori support,' especially at the end-of-life. Spiritual care workers are usually included as part of palliative care teams. This may include chaplains, spiritual leaders from the community, Māori spiritual leaders, as well as traditional healers. Having the links with iwi, Māori communities, and indigenous healers will enable contacts to be made with Māori spiritual support people; this can include practitioners from different faiths or those who practice more traditional spiritual *tikanga* (customs). This will determine whether the hospice service can meet this need when such Māori support is requested.

'The indigenous experience at the end-of-life is not dissimilar to that of Māori. Indigenous peoples' constructs of death and dying differ from the Western medical model… Death is typically viewed as part of a continuum, or a wheel, where the spirit transitions to another phase.'[51]

Māori spiritual beliefs and traditional customs will be expressed in a variety of ways by patients and their whānau, including recognised Christian faiths. Traditionally, the end-of-life is viewed as a time when the space between the world of the living and the spiritual realm, becomes 'thin'. Relatives and friends gather to ensure the person who is dying is not left alone while those relatives or ancestors, who are no longer part of the world of the living, gather and wait on the other side of the ārai (veil), in order to accompany the person's spirit on the last part of their journey.

Concepts of tapu and noa (often described as the contrasts between the 'sacred and profane' or 'forbidden and the ordinary') are highlighted at this time amongst Māori gathered around the dying person. The tikanga policy may outline how tapu and noa is viewed in a health setting – Māori hospital health teams developed and shared their policies to the sector. One such example can be found at ***https://www.ccdhb.org.nz/our-services/a-to-z-of-our-services/maori-health/#tikanga-maori-a-guide-for-healthcare-workers***. Te Wāngana o Aotearoa deliver regular podcasts which they describe as Tikanga 101 ('the regular series is named 'Taringa' or 'Ear'). One of these podcasts features discussion on Tapu, its application in historical and contemporary times. ***https://soundcloud.com/tw-oa/sets/taringa***.

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[50] McGrath, P. & H. Holewa. (2006). The Living Model: A Resource Manual for Indigenous Palliative Care Service Delivery. Toowong, Queensland. Researchman

[51] Mason, Kat, and T. Moeki-Maxwell, (2018). Māori and Palliative Care: Literature Review Report for Te Ohu Rata o Aotearoa (p10-11)

The gathering of a large number of people around the dying Māori patient can present a challenge if this occurs in an inpatient unit. Having policies that outline processes in place, the resources and the space for whānau to gather are important considerations for a hospice. Another inpatient unit issue that often concerns Māori whānau is whether the room has been blessed and spiritually cleansed following a death, before they move into that room.

Whānau and relationships become a source of spiritual support for patients and carers. Connecting with the wider natural environment is also an important aspect of wairuatanga (e.g. bush, gardens, waters, natural landmarks like mountains, lakes and the ocean). This may include landscapes significant to their traditional tribal landmarks. Clean water, blessed water, running water, or access to 'water features' which can be used to sprinkle or gently splash is important for spiritual care and cleansing. Other forms of creative expression (such as art, song, music and storytelling) may be introduced to provide emotional and spiritual connection.

To acknowledge and strengthen the spiritual side, the Kaimahi Hui in 2018 also made a range of recommendations.

Hospices could:

- *Identify spiritual distress, actively but gently.*
- *Integrate a spiritual assessment as part of the assessment for development of the individual care plan.*
- *Check whether the identified whānau individual who becomes the conduit for clinical communication for the whānau is the person who takes on the role of spiritual carer or whether other individuals may need to be identified.*
- *Actively support links with Māori communities, to identify kaumātua who are gifted with the role to run community or whānau karakia services, or Māori from other faiths or traditions.*
- *Provide booklets of waiata, himene and karakia which could be used by whānau (whether they are in an inpatient unit or at home) so whānau can manage their own services and provide comfort to the patient.*
- *Ensure that the communication skills, especially the listening skills are maintained.*

Kaimahi Hui – Te Tii, Northland, 2018

Te Pāmamae, te Tangi me te Pāpōuri: Grief, Grieving and Loss

> *Te pāmamae*, grief, the affliction of pain, pervades life. This view is affirmed in the Māori ritual of encounter, the *pōwhiri*, that greets both the living and the dead. Grief is made acute by bereavement, but it starts at birth. Everything that is created will be taken away. Grief is episodic, but also continual. Each individual loss is a reminder of every other. Grief is personal, but shared. My grief is a reminder of yours, yours is a reminder of ours. We make this point to emphasise that grief is much more than just a psychological phase of adjustment that individuals must go through in the time after death. It is an expression of *Te Taha Wairua*, the spiritual aspect that weaves through everyone's life and the wider environment – just as mist weaves together sky and the earth.

Hospice services acknowledge grief and loss by providing bereavement services to families after death. Counselling services are often available for grieving family members, recognition and reflection services are regularly held for staff (often weekly) and Remembrance Services are offered on a regular basis sometime after the death of the family member.

Māori processes such as *pōwhiri* and *mihi whakatau*, *whakawhanaungatanga*, *kawe mate* and *tangi*, are the means by which Māori focus on attention on Te Taha Wairua, or the spiritual side, where grief, especially recent grief, is expressed and often expressed repeatedly.

Whakawhanaungatanga (a process of self-introduction) provides the space where relationships and connections can be acknowledged, and trust developed. Lacking a formalised Māori process (*pōwhiri* or *mihi whakatau*) on entering the hospice service, the initial assessment is perhaps the closest to this process. Health workers in hospice should be supported to view this as part of a process of establishing a relationship (rather than a collation of medical history). When managed with good listening skills, it will permit health workers in hospice to understand the grief that whānau carry. Such understanding cannot be expected to be instant but must grow in parallel with the relationship. The relationship can not only exist in positive emotions but has to be prepared for more negative ones, when they occur.

There will be many aspects to the grief that whānau express. Expressions of grief are particular to whānau situation and culture, including multiple past experiences of grief. Hospice services can be mindful that each whānau expression of grief reflects the weaving together of past and future events. Although some expressions (especially anger) may be professionally challenging, there is always an underlying reason. The quality of the relationship can help hospice workers to better understand and help.

Tangihanga and **kawe mate** are traditional customs and rituals to help whānau process, release and express grief within a context where whānau support is available. Without observing these rituals, or in circumstances of multiple grief, many whānau may carry their sorrow and pain for longer periods of time. Consequently, guilt and regrets can linger longer without specific cultural opportunities to cry, laugh, and remember again.

Grief in a Māori setting is visceral, it is not necessarily 'polite'. It is experienced cognitively, physically, emotionally, spiritually, and even environmentally or spatially, and this takes place within the context of the larger whānau. Grieving is relational on every level. Within this setting it is also important to remember, to laugh, to weep, to sing and play, and to share food.

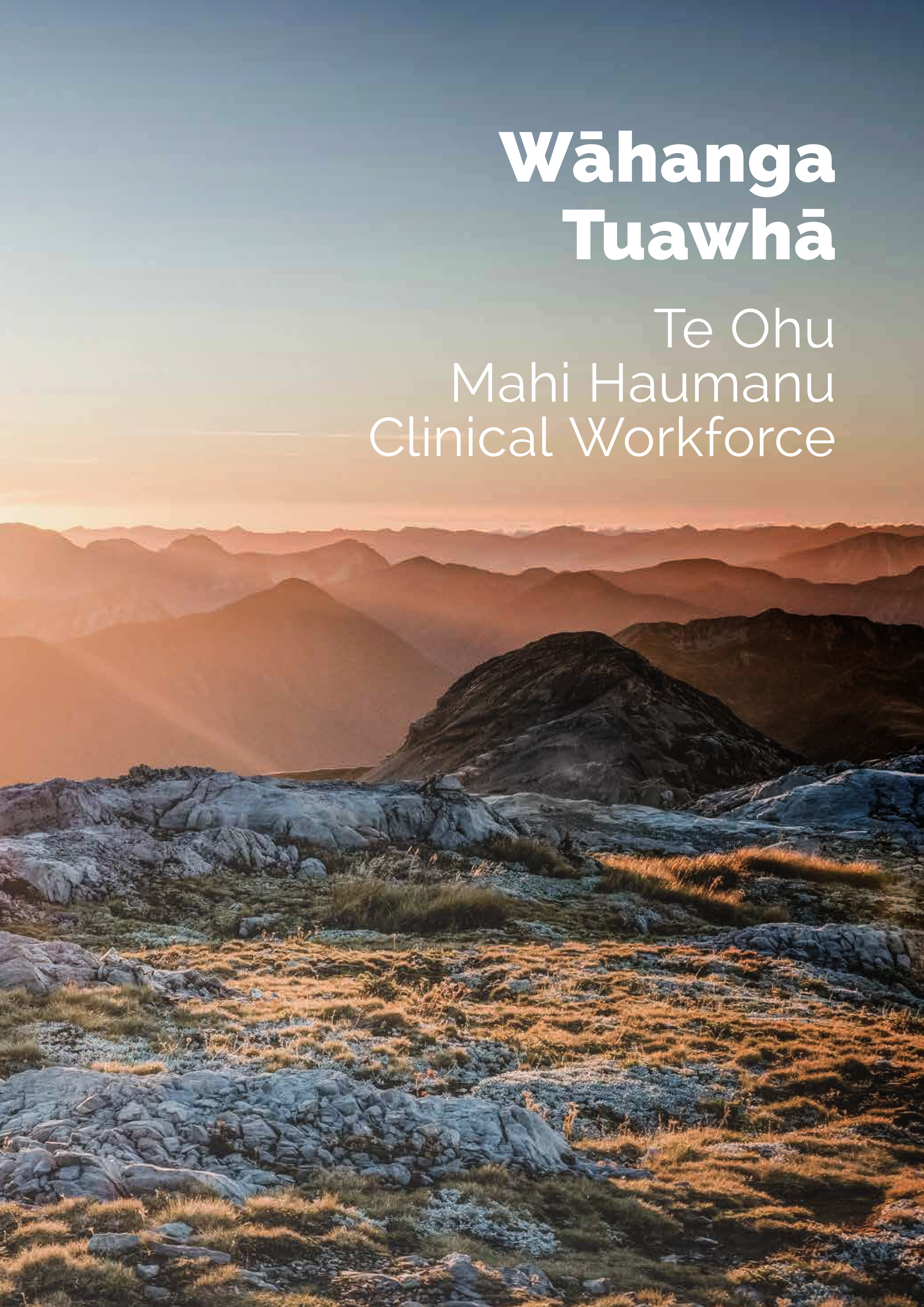
As has been indicated elsewhere, the effects of urbanisation where family members are scattered, the loss of kaumātua skills and the diverse realities of whānau and mixed marriage mean that the knowledge or use of these processes to express and release grief may be at greater risk. The Māori Liaison or Cultural position may be called upon to assist whānau make the linkages. This can be very difficult if there has been no relationship or relationships have fractured over time. Other issues that can be incorporated into the cultural or awareness training provided to hospice staff include:

- expressions of grief at a given time may include anger. Managing this expression of grief in an environment where anger is not tolerated can be a challenge. Where it is accepted and given the space to be expressed it can be an effective approach to supporting a person managing grief, provided there is no danger of harm to the whānau member or others.
- whānau strife and concerns as to arrangements for *tangihanga* and conflict over the final 'resting place' cemetery may occur following death. Traditionally this is a process of whānau decision-making (rather than the decision of a spouse or one individual). In fact, it can be considered a mark of respect to compete for the honour to host the tangihanga and place the *tūpāpaku* (*deceased person*) in the tribal or *hapū* burial grounds. It can of course, be very stressful especially where the spouse and/or children identify as another ethnicity. The spouse has stronger legal rights than Māori whānau of birth (where the traditional rights reside in Māori lore). This in turn may conflict with individuals holding an Enduring Power of Attorney (EPoA) in health and social services, who legally hold the 'decision-making power' ***prior*** to death for the dying person, when that person is medically 'not competent' or unable to make their own decisions. The Executor of the Will has legal responsibilities after death.
- feelings of guilt over unfinished business including situations where whānau felt they 'failed' in their care of the patient, especially the end-of-life – helping them to 'forgive themselves' or 'forgive others', is an important process as guilt can be carried for years.
- awareness of the spiritual presence or *wairua*, after death, often through the first year. Processes such as *kawe mate* sometime after the death (where the grief rituals are taken to groups of significant people who were unable to attend the *tangihanga*) or the *hura kōhatu*, the 'unveiling' – the placing and blessing of headstone, often a year later.

Complex grief and distress can be recognised and may require other services. In the practical approach to grief we support the use of *pūrākau*, traditional storytelling techniques, where whānau draw strength by relating their experience to *ngā atua me ngā tūpuna*, the actions of gods and ancestors.

Rārangi maunga,
tu tonu, tu tonu.
Rārangi tangata,
ngaro noa, ngaro noa

The mountains are
still standing...
long after the
people have gone



Wāhanga Tuawhā

Te Ohu Mahi Haumanu
Clinical Workforce

Te Ohu Mahi Haumanu:

Clinical Workforce

Hospices have identified the requirements to be classed as a specialist service professional and a specialist multi-disciplinary workforce.[52] Training requirements are also outlined within each of the boundaries set by each professional 'training registration body'. Within the span of roles that have or could be developed, there are those that rely on relevant conferences, training programmes or workshops organised by hospices (or related health organisations) and Hospice New Zealand networks, to provide ongoing training in wider palliative care skills.

Many hospices have staff who focus on education and training and quality processes. The training outlined throughout this document can be developed internally (using local and/or internal expertise) or sourced/contracted externally (through the community or networks). This section outlines the type of training that could provide or enhance the skills set we have discussed in this document.

Treaty of Waitangi

A number of experienced facilitators have developed Treaty of Waitangi courses that would assist hospice workers to understand how the Treaty could apply today. There is no standard set of 'Treaty' courses so a hospice may need to search for the right input or look at what other hospices have done (link through Māori Liaison workers) or to develop, over time, short workshop-based courses.

The Treaty focus includes a range of topics, such as; key historical perspectives on the Treaty, the Treaty in health legislation and policy, the contemporary Māori health Treaty claim before the Waitangi Tribunal, institutional racism (or bias) and Māori health policy and issues. This is also an opportunity to highlight and explore local iwi relationships, stories and perspectives.

Cultural Safety and Cultural Competency

As with the training on the Treaty of Waitangi, there are no set standard training courses for hospice workers in cultural safety or cultural competency. Nursing courses have long held cultural safety as part of their training programmes.

Developing training and resources in this area will require expertise found outside the hospice sector and we assert that workshops focused on cultural safety from the perspective of the patient and whānau, is the critical priority.

Cultural competency (as outlined in Wāhanga Tuatoru) is appreciated and is seen as valuable in relationship building but can sometimes be mistakenly considered as a substitute for cultural safety awareness. Other topics within this focus include cross-cultural communication, health literacy issues, tikanga policies, cultural awareness, and te reo Māori (especially pronunciation and including waiata and karakia).

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[52] Ministry of Health. (2017). Review of Adult Palliative Care Services in New Zealand, https://www.health.govt.nz/publication/review-adult-palliative-care-services-new-zealand

Communication skills

The literature review highlights the importance of skilled communication with Māori patients and whānau in the provision of good palliative care. Any training to improve the interpersonal communication skills of the whole hospice workforce (including volunteers and staff from those areas not specifically mentioned in the clinical sections of this framework), will benefit the whole hospice service.

In relation to this framework, the communication skills that have been outlined include:

- Cross-cultural communication skills
- Group facilitation skills
- Challenges and communication within a multi-disciplinary team

Training in this part of the framework also includes communication focused on 'what matters' from the whānau or patient's perspectives, often referred to as having the 'difficult' conversations about anticipating death and dying. Professional training is available to the clinical teams (both basic and advanced communication skills) and has been deemed very important to the discussion with patient and whānau. In addition, the support or training opportunities given to colleagues in other parts of the sector on this specific area may well address a real concern expressed in the research findings about the frequency of late referrals to palliative care and its impact on Māori patient and whānau.[53]

Recommendations

Hospices develop workforce training development plans that include training on the Treaty of Waitangi (with a focus on health) for all hospice health professionals and available to all staff and volunteers.

Hospices develop staff training on cultural safety and cultural competency, with supporting resources, that describe Māori diversity, Māori preferences and hospice resources, that meet the needs of Māori patients and whānau.

Hospices continue to support advanced communication training around the 'difficult' conversations around death and dying – not only providing courses for their own staff but providing opportunities for their health colleagues across the sector.

Hospices develop specific resources to support improved awareness of, and knowledge about palliative care services, how to access services and entitlements.

Hospices develop specific training for all staff to use these resources in engaging with Māori patients and whānau.

Hospices regularly collect and reflect on feedback from Māori patients and whānau about information on palliative care services, access to palliative care services and entitlements. This information can also assist to highlight issues for training.

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[53] Mason, K. and T. Moeke-Maxwell. 2018. Māori and Palliative Care, Literature Review Report for Te Ohu Rata o Aotearoa. Te Ārai Palliative Care and End-of-Life Research Group, School of Nursing, Faculty of Medicine and Health Sciences, University of Auckland. Unpublished report.

Te Ohu Mahi Māori: Māori Workforce

Māori Liaison or Māori cultural workers

The Māori workforce has been growing incrementally since the 2001 Palliative Care Strategic Plan was issued by the Ministry of Health[54] where an increase in the Māori workforce in palliative care was first raised as a strategic goal, with the largest growth occurring in the roles of Māori Liaison or Māori cultural workers. This continued to occur, albeit slowly, despite the acknowledged loss of Māori health leadership in the sector.

However, the workforce is 'fragile' with a number of Hospices either not yet creating a position with this Māori focus, or continuing to operate with a sole Māori in this position, or choosing to combine the role with the Pasifika Liaison or another role, or relying solely on Māori volunteers. Many are part-time employees.

Given the span of potential work outlined in this document (from cultural knowledge, relationship building skills, promotion and education as well as strategy and planning) it is important for boards and management of hospices to recognise that not all these skills would be necessarily found in one person, especially if that person is working part-time. In addition, being the only Māori on staff is a very lonely position – using linkages with other organisations, advisory groups and volunteers has been important for staff in these positions to gain support and stretch across the skill base.

Research findings support appropriate workforce development to better meet the needs of Māori with palliative care needs and their whānau. Findings include increasing the number of Māori working in palliative care (Frey et al., 2013; Koti 2013; Penney et al. 2009) and palliative care training for all services and providers that contribute to palliative care (Penney et al., 2009) including appropriate training for Māori health providers (Kara, 2008).[55]

Kaimahi Māori – Māori Hospice Workforce

Hospice New Zealand supports the annual Kaimahi Māori network hui as a professional hospice network. Hospice management are also asked to support the attendance of Māori staff to the hui to be updated on key palliative care and Māori health issues and to maintain support networks for their work. This hui is unique amongst the professional networks supported by Hospice New Zealand, in that individual members volunteer to jointly host (with Hospice New Zealand) at a marae the 'next year's hui' (with the support of the local Chief Executive) – this often means that hui are held in more isolated areas of the country that are more expensive to attend. It is considered as critical training and support for all Māori hospice staff, regardless of the position they hold.

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[54] Ministry of Health, 2001. Palliative Care Strategy, https://www.health.govt.nz/publication/new-zealand-palliative-care-strategy

[55] Mason, K. and T. Moeke-Maxwell. (2018). Te Ārai, Palliative Care and End-of-Life Research Group, School of Nursing, Faculty of Medicine & Health Sciences , University of Auckland). Māori and Palliative Care, Literature Review Report for Te Ohu Rata o Aotearoa (p13).

Kaimahi Hui 2018, held at Te Tii, Northland, considered the issue of Māori staff workforce and development. Key points in this section of the workshop include;

- Recruitment, support and respect for kaumātua advisors (paid role preferred, where possible)
- Māori recruitment across the full range of professionals (e.g. the first Māori music therapist at Waikato Hospice) – a structured approach to recruitment, training & support, and retention – allow Māori staff to meet and support each other.
- Use Māori staff to promote, encourage, meet and support each other.
- Opportunities to learn or upskill in waiata, karakia, whakapapa and te reo.
- Hospice New Zealand – Māori portal to access what has been done, what is already there, what's being done around the country.
- Encourage caring whānau into health professions/ volunteering.
- Cultural supervision, developing cultural confidence (linkage to local iwi, hapū involvement). Kaimahi should be able to choose their supervisors (kuia / kaumātua / community / kaupapa Māori health providers.
- Māori representation on boards and in management roles.

To increase the numbers of Māori on staff, successful means have included targeted approaches (e.g. job description; Māori training scholarships; advertising through Māori networks; and/or using Māori staff recruitment expertise) as well as opportunistic approaches (e.g. training placements of Māori health programme students, acknowledging skills of Māori applicants applying for generic roles, promotion at Māori health events or lecturing/presenting to health students).

The Ministry of Health document summarising two key research projects on palliative care and Māori health literacy, commented on two key research findings: concerns about the low levels of cultural competency and the low numbers of Māori in the palliative care workforce. This, the authors assert, will:

"...undermine confidence among patients and whānau in the capacity of the workforce to deliver quality palliative care for Māori that meets their palliative care needs. [They also acknowledge that there is] a long standing and enduring under-representation of Māori in the palliative care workforce."[56]

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[56] Ministry of Health. (2014). Palliative Care and Māori from a Health Literacy Perspective. Wellington (p61)

Māori Volunteers

Volunteering is an important concept in hospices. It is part of the foundation of hospices as functioning charities. Volunteers in hospices are valued, nurtured and trained and do a wide range of tasks that add value for patients and whānau in hospice services. This was traditionally focused on the inpatient unit and is now active in the community.

Surveys by the Ministry of Social Development indicate that Māori are active in volunteering, but from anecdotal sources, Māori volunteers are more likely to be active in different types of family and community areas (e.g. sports, marae, te reo maintenance, social services), than hospice services. (Although, anecdotally, Māori volunteering in hospice shops seems to have increased.) See Volunteering NZ website for information – ***https://www.volunteeringnz.org.nz/research/Māori-pacific-islands***

The same principles that apply to the recruitment of Māori staff, apply to the recruitment of Māori volunteers – targeted and supported recruitment, training and retention approaches are required. Hospices could apply the principles of *koha* and consider what value could be or is, 'exchanged' or 'gifted'.

Recommendations

Hospices develop Māori workforce development plans that support measureable increases in the Māori palliative care workforce, and support career development of Māori staff in hospices. These plans should include the need for specific cultural roles and specific measures to describe progress.

Plans should include recruitment, training, retention and succession planning approaches.

Āpitihanga

Appendix

Āpitihanga 1: Ngā tautuhi o te mahi pairuri
Appendix 1: Palliative Care Definitions

New Zealand Definition

The Palliative Care Subcommittee of the New Zealand Cancer Treatment Working Party (2007) developed a working definition of palliative care for New Zealand. Palliative care is the care for people of all ages with a life-limiting illness, which aims to:

- optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs
- support the individual's family, whānau, and other caregivers where needed, through the illness and after death.

The principles of palliative care service provision are that it should be:

- provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away
- available wherever the person may be
- provided by all heath care professionals, supported (where necessary) by specialist palliative care services
- provided in such a way as to meet the unique needs of individuals from particular communities or groups, including Māori, children and young people, immigrants, refugees, and those in isolated communities.

Ministry of Health. (2013). Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand, Wellington

World Health Organization (WHO) Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Extracted from ***https://www.who.int/cancer/palliative/definition/en/*** (March 2019)

Āpitihanga 2: Ngā Take Matatika
Appendix 2: Ethical Issues

Cultural & Clinical Integrity

In the Western medical tradition, there are four cardinal ethical principles: autonomy (individual decision making); beneficence (doing good); non-maleficence (minimising harm); and justice (fair use of available resources). (Twycross, R. et al, 2016) (Gillon, R., 1994)

In this Western medical approach, there is a bias in favour of 'autonomy' and this may conflict with understanding how the decisions on treatments or choices around care may impact on the whānau or how whānau may contribute to the decision making.

Clinical integrity is a way of applying the cardinal principles – for good care of Māori we would place emphasis ***on both*** patient and whānau 'values, needs and wishes and the integration of the best available care or treatment'. (Twycross, R. et al, 2016) (Palliative Care Council of New Zealand, 2012)

In Aotearoa we can also look for guidance to the Nursing Council of New Zealand (NZNO) and the New Zealand Medical Council (NZMC). The NZNO has its Code of Conduct which includes clinical ethical and cultural competence. The NZMC has a range of documents and statements which set out requirements for cultural, ethical and clinical competence for medical practitioners.

There is clearly a role for respect of whānau within palliative care. (Palliative Care Council, 2012) This framework considers whānau as central to good palliative care and hospice care for Māori. For Māori, whānau is about the wider family structures as well as the immediate family and may include people with close relationships who are outside the whānau.

An understanding of the social structures around any hospice patient, a sense of who they are and how they relate to others and their whānau, what their financial situation is, how they view spirituality, are all part of a foundation for good hospice palliative care. (Palliative Care Council of New Zealand, 2012)

While Māori frameworks, such as 'Whare Tapa Wha' are widely applied (to all ethnic groups) in hospice practice, we want to explore a few Māori concepts that we consider important in hospice care.

In Māori culture, we believe in caring for a person, who has a limited time to live, in a way which upholds their *mana*. Mana is 'a strength emanating from within a person, from their spiritual, mental and emotional being'. Mana is to be respected in providing palliative care. (Palliative Care Council of New Zealand, 2012)

Manaaki is central to Māori thinking. It can be defined as 'to support, take care of, protect, show respect'. (Palliative Care Council, 2012). Manaaki in palliative care would mean providing care with 'a nurturing and loving spirit'.

Emotional wellbeing is part of the holistic care that hospice aspires to provide for patients and their families. Spiritual wellbeing is another facet to providing holistic care.

These aspects place importance on the interdisciplinary professions and teams; including the Māori cultural support person, spiritual carers, psychologists, social workers, counsellors, occupational and physical therapists. The integration and communication of the wider team with the medical and nursing expertise is vital in providing good palliative care. (Palliative Care Council of New Zealand, 2012)

Āpitanga 3: He Ara Tohu

Appendix 3: A Roadmap - A Māori Palliative Care Framework for Hospice

Wāhanga 1: Te Horopaki – Context

	Aim	**Recommendations/suggestions**
Purpose Te Tiriti o Waitangi Equity Palliative care and hospices Whānau at the Centre Relationships with Māori communities	Understand the palliative care context for Māori. Ensure whānau are at the centre. Value and build relationships with Māori communities Honour Te Tiriti o Waitangi.	● Implement the Aims of Wāhanga 1.

Wāhanga 2: Te Ao Hurihuri – Contemporary Social Overlay

	Aim	**Recommendations/suggestions**
Understanding population Social complexity Diverse whānau, diverse experiences Inter-generational trauma Māori preferences for communication Information	An understanding of the diversity and complexity of caring for whānau. Awareness of the effects of colonisation and intergenerational trauma. Knowledge of Māori preferences for communication.	● Obtain regional Māori population statistics. ● Engage with local iwi and Māori communities. ● Care plans are formed with whānau and remain updated. ● Identify kaupapa Māori services e.g. counselling, Rongoā Māori, wairuatanga and mental health. ● Ensure care approaches allow appropriate time. ● Communication is less formal and free of medical jargon. ● Specific information packs for Māori whānau are tested and developed describing palliative care service and journey

Wāhanga 3: Ngā Ratonga Haumanu – Clinical Services

	Aim	**Recommendations/suggestions**
Cultural Safety and Cultural Competence	Patients/whānau find service culturally safe. Deliver culturally competent care.	● Cultural safety and cultural competency training occurs. Critical self-reflection is effective. ● Develop appropriate relationships with those able to deliver education. ● Development plans include cultural safety training for all professionals. ● Training and resources describe Māori diversity, Māori preferences and resources meet the needs of Māori patients and whānau.
Clinical Communications	Understanding around: ● What matters to patients/whānau at the end-of-life. ● What is happening now and how that might change. ● What are options now and in the future. ● Masterful communication that supports care and bereavement.	● Access/utilise health information that is appropriate for Māori e.g. written, visual, social media, digital stories. ● Develop health information and resources that are appropriate for Māori e.g. written, visual, social media, digital stories. ● Effective communication between peers and colleagues occurs (internal and external) ● Effective communication with external health partners occurs.

Wāhanga 3: Ngā Ratonga Haumanu – Clinical Services *continued*

	Aim	Recommendations/suggestions
Rongoā Māori	Recognition of Rongoā Māori and that at its core is the enhancement of Māori wellbeing.	● Local practitioners are identified for referrals and learning ● Staff enquire if whānau are using Rongoā Māori or Rongoā rākau. ● Further research into Rongoā Māori in Palliative Care is supported.
Clinical care	Assessment occurs to capture and support Whānau preferences or needs in respect to Tikanga Māori. Recognition that caregiving practices by Māori may incorporate traditional customs, and that cultural customs may increase caregiver resilience.	● Hospices specifically enquire and engage with Māori patients and whānau around their intentions, preferences or needs in respect to Tikanga Māori. This is recorded in care plans and visible to patient and whānau. ● Significant time may need to be invested to support capability and wellbeing of carers. ● Data is evaluated in day and community programmes to identify any need for change. ● Consumer feedback or quality audit processes be developed that are appropriate for Māori. ● Cultural audit tools may be developed to identify gaps, service change and training.
Special care needs	An understanding of care for those with special needs e.g. ● Rural Communities ● Prisoner Health ● Caring for Carers ● Tāngata whaikaha – Māori with a Disability ● Sexual orientation, sexuality and intimacy	● Programmes and initiatives that aim to support caregivers be monitored, reviewed and assessed to identify whether Māori patients and whānau are accessing such programmes and how they are being viewed by Māori. ● Build awareness and connections to local justice services and specialist health and community organisations.

Wairuatanga – Spirituality	Respect of cultural traditions of indigenous peoples including the religious or spiritual nature. Understanding that death may be viewed as part of a continuum for Māori.	It is suggested: ● Foundations of Spiritual Care programme be shared ● Those that interact with Ao Māori are likely to seek support from wider whānau or Māori communities ● Support links with Māori communities to identify kaumātua gifted with the role to run whānau services, or clergy from other faiths and traditions ● Support with booklets of waiata, himene and karakia ● Access to clean water, blessed water, running water or water features may be important for spiritual cleansing
Grief, grieving and loss	Awareness that grief is much more than a phase of adjustment post death. It is an expression of Te Taha Wairua, the spiritual aspect that weaves through everyone's life and wider environment.	It is acknowledged: ● Each loss is a weaving of past and future loss ● Whakawhanaungatanga will make space for trust ● Tangihanga and kawe mate are rituals to process and express grief (without these sorrow and guilt may linger) ● Grief can be experienced cognitively, physically, emotionally, spiritually, environmentally or spatially. ● It may be important to remember to laugh, weep, sing, play and share food. ● There may be challenges or strife around tangihanga preparation or final resting place. ● Pūrākau or traditional storytelling are preferred methods so whānau can draw strength from relating their experiences to gods and ancestors.

Wahanga 4: Te Ohu Mahi – Workforce

	Aim	**Recommendations/suggestions**
Clinical Workforce	Staff understand Treaty of Waitangi and commitment in a health setting. Delivery of culturally safe care by culturally competent people. Masterful communication is experienced in the sector.	● Develop Treaty of Waitangi training for health professionals. ● Training is available to all staff and volunteers. ● Develop cultural competency and cultural safety training. ● Support training around difficult conversations around death and dying for staff and colleagues across the sector. ● Develop specific resources regarding palliative care services, service access and entitlements and all staff have training on how to use these resources. ● Feedback is sought regularly on palliative care services, access and entitlements and may be used to highlight training needs and quality improvement.
Māori workforce development	Value Māori Liaison or Cultural worker roles Conduct targeted and supported recruitment to increase number of Māori on staff. Conduct targeted and supported recruitment to increase number of Māori volunteers.	● Development of workforce development plans to support measurable increases in the Māori workforce. ● Career development of existing Kaimahi Māori staff is supported. ● Plans include recruitment, training, retention and succession planning approaches. ● Views and perspectives of Kaimahi Māori in the sector are acknowledged and valued.

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