

THE VOICES OF
UNDERSERVED COMMUNITIES
IN PALLIATIVE CARE

E tū Pōhutukawa

Te kaikawe I ngā mate o te tau

Haere rā koutou ki te uma o Ranginui

Hei whetū e te nui a Tāne

Koia rā! Kua whetūrangitia koutou kei

aku rau kahu rangi!

Behold Pōhutukawa

Who carries the dead of the year

*Onward the departed to the chest of
the sky*

To become a star in the Milky Way

*It is that! You have become stars,
amongst myriads of celestial
garments!*

Dr Rangi Mātāmua and Sir Pou Temara

Executive Summary

*In Aotearoa New Zealand people have differences in health that are not only avoidable, but unfair and unjust. Equity recognises different people with different levels of advantage require different approaches and resources to get equitable health outcomes.*¹

The impact of inequities on health outcomes is well established. There has been less attention paid to how these inequities impact on end-of-life experience. In particular, the voices of people from communities traditionally underserved by palliative care rarely feature in policy and service development. There is also very limited available information about the numbers of patients referred to specialist palliative care services from these communities. In this report we begin to address this gap by foregrounding the voices of people with lived experience of palliative and end of life care. The report is divided into three sections.

Section one provides a summary of existing evidence for each group, drawing from our own research and consultation, as well as systematic reviews of the published Aotearoa New Zealand (NZ) research literature. We also present two stories: one from a lived experience expert, and one from a service provider. These stories convey the resilience and resourcefulness of individuals who have faced significant inequities in their life. They also speak to the important work undertaken by service providers in often challenging situations.

Whilst we present these communities separately, we have identified common threads in terms of people's experiences of health and palliative care. Of note, people die younger and often in preventable ways. Palliative care need is complex due to multiple physical and mental health conditions and social circumstances which can amplify suffering. The healthcare settings in which palliative care is provided may not be perceived as safe, particularly when people have previous experiences of discrimination. Seeking care may also not be a priority given competing demands. This translates into people neither accessing specialist palliative care services at a level commensurate with their need, nor receiving generalist palliative care from their usual healthcare provider. Whānau and family also often feel unsupported during caring and bereavement.

Section two presents all available published evidence regarding Māori and Pacific experiences of palliative and end of life care. Each section was led by Māori and Pacific researchers and evidence analysed within relevant cultural frameworks. Overall, the findings indicate that there is still much to do to ensure culturally safe palliative care across all NZ health settings.

The third, concluding, section provides two resources to guide people who want to begin to address inequities in palliative care. He Tapu Te Tangata (The Sacred Person) is a conceptual framework developed from the Te Whakahekenga (Dying as a health and social justice issue) project findings. This framework acknowledges the need to respect the sanctity or the wholeness of a person and can be used as a practice guide for healthcare professionals. Finally, we conclude with principles to guide individuals and organisations who want to contribute to much needed equity efforts in palliative care. These highlight that, in any equity focused work, we need to start with ourselves and the organisations we work for.

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Introduction

This report has been produced during Matariki and celebrates the Māori new year with the ceremony called *whāngai i te hautapu*/sacred offerings to the stars. The opening karakia gives thanks to the [whetū Pōhutukawa](#), acknowledging that this is a time to remember those who have passed away.

We begin by providing a snapshot of key issues for nine communities underserved by palliative care: people experiencing homelessness; incarcerated people; people living in areas of rural deprivation, gang affiliated/related *whānau*, members of rainbow communities, people from refugee backgrounds, people experiencing serious mental illness, people with a learning disability, and children and young people. For each of these communities we present a story from a lived experience expert and a story from a service provider. These stories convey the resilience and resourcefulness of individuals who have faced significant inequities in their life. They also speak to the important work undertaken by service providers to deliver the best care they can, in often challenging situations. In addition, we provide an evidence summary for each community which synthesises the experiences of hundreds of other people to highlight what we currently know about their palliative care and end of life experiences. This information is based upon systematic reviews of all NZ-based published research and our own research and consultation. However, for most of these communities, the studies we have conducted are the first of their kind in NZ and more work is needed to fully understand the diverse end of life circumstances people experience.

It is also important to note that this report does not cover all communities underserved by palliative care and that these communities are not mutually exclusive. For example, people experiencing significant mental illness and members of the Rainbow Community are over-represented amongst those experiencing homelessness. Children and young people feature in all groups. Māori and Pacific people are over-represented across all communities facing inequities due to the on-going effects of colonisation. Whilst we use the term ‘community’, we also recognise that there is significant diversity within each group.

Whilst we present each of these communities separately, we have identified common threads which run across all groups in relation to people’s experiences of health and palliative care. First and foremost, there are commonalities in terms of the strength, resilience and creativity of people from underserved communities. These skills are applied to end of life, as is evident in the stories you will read. Also evident are the ways in which people express [mana motuhake](#) and [rangatiratanga](#) in the face of the often multiple systems of oppression to which they are subjected, including colonialism, racism, ableism, homophobia, and transphobia. Identifying ways to support people’s agency to determine their end-of-life experience, and that of others in their community, is an important priority moving forward.

Also of note is that people across most of these communities die younger than the population as a whole and often in preventable ways. Palliative care need is complex, with many experiencing multiple physical and mental health conditions, as well as social circumstances which can amplify suffering. These deaths also often look different from the “typical death” seen in palliative care. For example, death can appear sudden. However, when previous health issues and the circumstances in which the communities are living are considered, death is often not unexpected. Across many of these communities, deaths from suicide, violence, and drug and alcohol addictions are common. In addition, experiences of previous trauma from violence, abuse, colonisation, discrimination and in the case of refugee’s war and displacement, is evident. The resulting grief is profound for family, friends and the wider community, as well as for health and social care providers.

It is important to recognise that most in these communities are not just underserved by palliative care, but by healthcare in general. Institutions, including mainstream health services, are often not perceived as safe spaces. By extension, the health professionals who work there may not be trusted. In addition, seeking healthcare, even in the face of serious illness, may not be a priority. This makes sense if the choice is between getting food to eat and attending a health appointment. Or, if the nearest hospital is two hours away, there’s no public transport, and you’re not able to drive. Or, if during your last healthcare experience, you felt judged and stigmatised. Therefore, not only are people not accessing specialist palliative care services at a level commensurate with their need, but they are also not receiving generalist palliative care from their usual healthcare provider(s). Indeed, many do not have a “usual healthcare provider”, such as a general practitioner. *Whānau* and family, who frequently encompass family of choice rather than biology, also often feel unsupported during caring and bereavement.

Whilst people from underserved communities can have positive experiences of receiving specialist palliative care, it is clear that this care needs to be much more accessible. New approaches are needed which recognise that interacting with mainstream health services is often not seen as safe by those who have experienced a lifetime of discrimination, stigma, and trauma. Trust, which takes significant time to establish for people who are distrusting of the healthcare system, is fundamental to appropriate help being identified and accepted from health and social care professionals. Ways of working with individuals and organisations with whom people already have trusting relationships, most of whom are not healthcare providers, must be developed. Crucially, any solutions to inequities must be formulated in partnership with those whose expertise is rooted in lived experience. Otherwise, they just will not work.



Merryn Gott



Jackie Robinson



Stella Black

Te Ārai Palliative Care and End of Life Research Group



Section 1:

LIVED EXPERIENCE OF PALLIATIVE CARE

Palliative Care in the Homeless Community



Context

- Homelessness includes situations such as rough sleeping, couch surfing, living in shelters and women's refuges, living in severely crowded dwellings, and living in cars.
- At the 2018 Census, there were over 41,000 New Zealanders, or nearly 0.9% of the population, experiencing homelessness.
- Māori and Pacific people's rates of homelessness are nearly four to six times higher, respectively, than Pākehā.
- The life expectancy of homeless persons is 20-30 years shorter than in the housed population. Deaths occur mainly alone, in public spaces or in private vehicles.
- Three-quarters of homeless people die from conditions amenable to timely and effective healthcare interventions.
- The homeless community experience a high incidence of mental health issues, addictions and past trauma, including violence and abuse.

Contributors

- Jackie Robinson, Stella Black, Merryn Gott and Janine Wiles contributed to this section.
- Stories were collected as part of the Te Whakehekenka: Dying as a health and social justice issue study, funded by the Health Research Council and conducted in partnership with Te Tāpui Atawhai/The Auckland City Mission.

Harry's story

We're the biggest city in this country and there's no night shelter. That's stupid, as far as I'm concerned. Some people don't wanna get a place, we just need somewhere to sleep for a night or two. Somewhere that opens for an hour at night when you can come in. The doors are locked and, in the morning, we get kicked out at 7am or whatever. Once you're in, you're in, you can't get out. But if you're not there, well, you're not there. You could even have a shower if you got up early enough. I'd had a job when I was staying at the night shelter so I'd just get up early in the morning and have a shower, 'cause the lady who ran it would wake me up.

I used to be a chef and manage a kitchen, but the incompetence just does my head in. If I can do it better myself, or if I'm doing your job as well as mine, yeah, no, it just gets too much. But generally, I try the best I can to look after myself and I just try not to hurt other people too, that's all I try and do. I can handle myself. Threats are idle threats to me, especially since my heart attack. But for other people, it's not good, you know? I was working in this kitchen and one of the girls was getting a really hard time from this lady. I just said to the lady you can't tell them what to do, you're not their boss. She and her husband are awesome dudes, and cos I stood up for her, we've been best friends ever since. They come to visit me here.

I used to live on a farm in the country when I was a kid, we had cows, goats, pigs and sheep. But then my mum went to jail. My sister and I got sent to foster homes. After about a year, my old man came and got me, and I went to live with him and his new family. His new wife already had three kids. I always felt like the second mate. I probably wasn't the easiest, always misbehaving. I was a real little shit sometimes. Then I got sent to Australia, I was abused over there big time. I can't remember a lot of what happened but maybe that's a good thing. The drugs and alcohol help me to forget and they help me to sleep better too.

The medical care's alright at the Mission, I don't mind that. After my heart attack the doctors gave me all these pills. I can eat them all with a knife and fork - breakfast, lunch and dinner. And I have a blood check now and again. They wanted me to go back and have another gastro thing, I told them to fuck off. Shoving a tube down your gob while you're conscious! And then the doctors and nurses, they get all pissed off when I fight them off. I try to tell them that they're choking me, but they don't listen. So of course I am going to fight them. Then they wanted to sedate me more and I say no...fuck that shit. I'm never going back for another one, never. I didn't like it the first time so I'm not going to like it the second time, am I? Also, the hospital tells you to get someone to pick you up, you're not allowed to leave by yourself, you're not allowed to do this or that. Fuck that, not doing that again.

The thing is all my life I just thought it was indigestion. That don't sound too bad. Age sounds worse and cancer is even worse. Indigestion don't sound that bad to me, I can take pills for that. Although I think it might be borderline cancer in the stomach which sounds bad but I don't care, I don't want to know. If I go, I go. It's not gonna happen. To be honest the sooner I go, the better. But God don't want me yet, eh? But he's not telling me why I'm here and that pisses me off.

Evidence summary

Death from suicide, violence and overdose is not uncommon in the homeless community. However, even when death is as a result of physical illness, death looks different from the “typical death” seen in palliative care. Death may appear ‘sudden’ but when previous health issues and living circumstances are considered, **death is often not unexpected**. Regardless of the type of death, there are opportunities in the homeless community to provide good palliative care. However, **attending to health issues is not a priority** for this community. Having basic needs met such as access to food, shelter and managing addiction take priority over physical health.

Several times I've had [acutely unwell] people say to me “Look.... I won't let you send me to the hospital because if I don't go to this appointment with the foodbank - there's no point in me living if I don't have food in my fridge” (Service provider).²

Late diagnosis is common because of the barriers accessing healthcare and **diagnostic overshadowing**. Previous negative experiences are underpinned by a lack of trauma informed care. Services are also set up for someone who has an address, a phone and transport. Barriers to access are compounded for Māori who report experiences of **racism**, as well as a **distrust of Western medical treatment** related to the on-going impacts of colonisation. Support workers confirm the discrimination the homeless community experience in mainstream healthcare:

I feel like the words are too deep and I might become too [emotional]. Like, ‘you're trash’, or ‘you're homeless...you've got no choice but to take what we're giving you’ (Service provider).²

The homeless community experiences **complex and significant palliative care needs** due to accelerated ageing, a high burden of multiple often untreated chronic conditions, histories of trauma, and experiences of addiction, all of which complicate pain management. Use of hospice is rare as people don't follow a typical palliative care trajectory and typically distrust institutional care. **Many feel unsafe in institutions** after previous experiences of growing up in state care and/or violent childhood homes, or prison experience:

I was more safe out on the streets than I was anywhere else. I never got harmed out there (Lived experience expert).²

This impacts **end-of-life decisions** about places of care and dying:

[My whānau clients] are coming from experiences of institutions, so, you know, so they would prefer to actually just go under the bridge and pass away there than having to be locked up (Service provider).²

Interactions with health care professionals and spaces such as outpatient clinics or the Emergency Department tend to be **confusing, confronting, uncomfortable and difficult** for street whānau, and for their supporters. Their presentation and behaviour may not align with norms of patient behaviour, so they feel uncomfortable in such spaces, and in turn are often perceived and treated as uncompliant or aggressive. There is **little evidence of a palliative approach to care** during healthcare interactions, or the life-limiting nature of diagnosed health conditions being explained in ways that people understand:

When he diagnosed me with that emphysema, they should have told me what it was. All they did was give me four letters. It's called ODC something. They only gave me four individual letters. They never actually explained to me (Lived experience expert).²

People experiencing homelessness know what is needed to manage their health and wellbeing, including at end-of-life. **Trusted and enduring relationships** must be the basis of support being accepted.

They'll tell their story to one person, [then] they get passed on and they've got to start all again. That's a no-no because they don't want to go through that, they've been through that all their lives. They just want somebody to be there with them right through the walk to the end (Lived experience expert & peer support worker).²

Many support workers have deep knowledge of the needs of street whānau and support health professionals to partner and liaise more effectively with street whānau; support workers with **lived experience** bring particular expertise to this role:

We know how to engage with our people and we understand 'cause we've had that walk of life with them (Lived experience expert and peer support worker).²

People experiencing homelessness identify need for **transport** to get to health appointments, or for **services that will come to them**. Access to **rongoā and counselling** is also welcomed. Support workers recognize a need to work with the homeless community in a way that **supports their autonomy**, often by showing up even in the face of challenging responses:

We remind ourselves that they are the experts of their own lives and we're just here to provide the options. It's up to them to make their own decisions just as we all make our own decisions (Service provider).²

These **trusted relationships can support dying**:

On the last day, in the hospital, she was kicking all the doctors and nurses out. So I'm glad that I came in, that she was familiar with me. I was saying "Okay, you listen to the doctors. Let them do what they need to do". It was either that day or the next day that she passed. She just didn't want to go into palliative care (Service provider).²

However, **many deaths are unjust** in the sense they are preventable, happening at a young age, and typically occur without support from friends or trusted support workers. There is a struggle for legitimacy in healthcare spaces where biological family ties take precedence.

What hurts the most is wishing we could have done more. And so often we know that as an individual [we are] maybe doing all we can, but there's so many breakdowns and barriers within the system that, you know this could have been prevented. Or, how people's lives could have been turned around at an earlier stage had the system actually been built to support our people instead of work against them (Service provider).²

A general practitioner's story.

George was in his 50's when I first met him. He had end stage heart failure and had been living on the streets for many years. As soon as he stopped taking his medication, he would become very short of breath, and then of course he would get severe oedema. We tried hard to simplify his medication regime, so he only had to take it once a day. The issue with medication, and particularly when you're thinking about, you know morphine and controlled drugs, is where can he keep them safe? The support worker was excellent. She would go out onto the streets and find George to give him his medication.

We managed to get George an apartment for a time, but he found it difficult living indoors. Sometimes he would sleep on the deck, sometimes he went back onto the streets for a while. He really felt a sense of claustrophobia being inside and all his community were rough sleepers. People just want to reconnect with their community, so they go back and sleep outside with them.

As George became more unwell, he wanted to reconnect with his family but like a lot of the people we work with, George had lost contact with them many years ago. His support worker managed to track down his brother, so he decided to move to be nearer to him and to where his mother was buried. But it was difficult to find somewhere for him to stay. The hospice wasn't an option as he could have still had months left to live. Eventually we found him a place at one of the small rural hospitals. They gave him fantastic care. His support worker and I went out to see him a few times. But again, he found it difficult being inside; sometimes he would go off and sleep outside.

I think many people have the same difficulty in accessing good end of life care as they have accessing primary healthcare. Maybe, they haven't had the funds to go to a general practice clinic, or they've had unpaid bills. Because of mental health and sometimes addiction issues, you know sometimes the behaviour is bad and they get a bad reputation. And they feel ashamed when they go to the medical centre to make an appointment. They need to be welcomed when they arrive and if people turn up late, we need to be able to see them. With hospital appointments, people may need help attending them. They may need to be reminded, they may need transport, they may need an advocate with them. Often health literacy is very poor, computer literacy may not be great. And sometimes, you know they are unable to read and that's sometimes I think something we often miss. Because it's something that people are ashamed of and so often people are very good at masking that.

Once you understand a little bit about the terrible lives people have had that counteracts being judgmental. I sometimes say to people, "Are there things that happened in your past which might still be affecting the way that you feel or behave today?" And I think it can be quite powerful for people to make the connection between the past trauma and the current malfunction. And I think that can take away some of the shame perhaps. If we can all offer trauma informed care, we'll be going a big step in the right direction.

Palliative Care for Incarcerated People



Context

- NZ has 18 prisons around the country.
- Due to the on-going impacts of colonisation, Māori make up 53.4% of the prison population.
- Many will enter prison with unmet health needs and most have been the victims of violence.
- Ninety percent of the people in prison have mental health needs, or issues with addiction; the likelihood of suicide for the prison population is higher than the general population.
- Healthcare provision in prison includes primary care and mental healthcare.
- Contracted health services for incarcerated people include pharmacy services, doctors, dentists and other primary health clinicians, while 243 nurses are employed by the Department of Corrections.

Contributors

- Jackie Robinson, Stella Black, Merryn Gott and Ruby Alexander contributed to this section.
- Staff from the Department of Corrections were consulted.
- The two stories were collected as part of the Māungarongo: *exploring the end-of-life care needs of incarcerated New Zealanders* study, funded by the Health Research Council.

Duke's story

I served a bit of time behind the bars. I want to share my [whakaaro](#) about the dying of many of our men, as well as [wāhine](#), within the [whare herehere](#). There was a lot of death in there, violent death, suicide and illness. But it didn't matter, whether it was a hanging, whether it was a gang killing, whether it was someone that was sick, when someone died, the ripples went through the whole prison. Everyone knew about it, but no one talked about it. You couldn't really miss it because you walked past his hut and his hut was empty. You might have someone that might have hung themselves or someone that might have died in their cells and then the next day they put someone in there. We mourn for probably a day or two. You know that the prison mourns because no one plays touch for two days, no gym for two days. No one. Everyone just walks around the yard talking. "No game today, brother." "No gym today. Yeah, brother, no gym today." Just walking around. And then you've got someone that has passed on and you've got those that are walking around just having a [kōrero](#).

And then we learnt our [Māoritanga](#), and it got to a point where, when someone hung themselves, we did our own blessings. And we'd say well, "I did the last one, you do that one." And we'd tell the officers, "I need someone to go and bless the room down there." "Oh, yeah, we'll go and do that." So yeah, we became tohunga in our own right, eh? The kaumātua might come in with about two or three kuias and two other kaumātuas. They might sing a bit of a song and then the boys go round, and they have a bit of a hongī and have a bit of a biscuit and a cup of tea, and it makes it feel a little bit better. It makes you feel a little bit better because we're doing something that's right for our brain.

The last one that I knew who died, his name was Reihana, everyone knew he was dying. We'd all sit around him, and he said, "oh, mate, I think I've only got two weeks." But he wasn't allowed to go home. Sometimes he would be screaming in pain. All he got was aspirin or some kind of pain killers. What the brother needed, what the brother really needed was his family. I think of the last one that had a heart attack in there. It took a long time for the ambulance. They were just trying to resuscitate him, that's all they could do until the ambulance got there, they stripped him and put the [doof, doof, doof]. Hell, he's been laying there for three hours, but he was still alive. He eventually died in hospital.

A lot of the men died in prison, they didn't go home, they didn't get any early release. Their only comfort was from the other men. They couldn't really shower themselves; they were lost and just sit and sometimes walk around. You see them wipe their mouth and see blood on their shirt and, "sit down, brother, sit down, my bro". They sit down and you said, "oh, bro, the brother's bleeding from the mouth, go and get the medical, get the medical." Yeah, compassionate ground you had to be like half dead.

So, in some cases you get a lot of the families, they ask why couldn't we have him at home for two days? Why couldn't we have him referred to the hospice where we could have visited him, where we could have had some time, just to have some time with his kids? When you have someone that dies in prison, and you only get the body when it's already gone, they ask the questions. But in saying that, there have been some men that have been released to go home, but that would depend on your crime. More serious, the less likely they'd allow you to go home.

Evidence summary

Incarcerated people typically have high and complex physical and mental healthcare needs before entering prison. These are also exacerbated by being in prison. As a result, they experience **age related physical deterioration** at an earlier age than the general population.

Many enter prison with **pre-existing undiagnosed mental health issues**. Seclusion and isolation are strongly associated with suicidal ideation. Being imprisoned is itself a risk factor for premature death

These structures of imprisonment, which expose prisoners to heightened vulnerability, dehumanisation and maltreatment, also make inevitable otherwise preventable deaths (Expert opinion).³

Accessing external healthcare providers can be a dehumanising experience:

I was escorted [to the hospital] by an officer, sometimes using the short handcuffs. When going to the bathroom I was cuffed up on the long chain handcuffs. I was also chained to my bed. I felt disgusted. I wouldn't chain my dog up like that (Lived experience expert).⁴

Access to specialist palliative care is inconsistent and impacted by the overriding need for security.

Yes, sometimes we provide physical care, but safety and security are one of the main purposes (Service provider).³

During an illness, people may require medication such as opioids that have a high value in the prison environment. Safety around these medications is prioritised and they are administered by nurses in single doses face to face. There are **no nursing staff on site 24/7** which creates difficulties when people need 'as required' medications.

There are **no dedicated units or beds** in the general prison environment for people nearing the end of their lives. There is one 30-bed **high dependency unit** (HDU) in Rimutaka Prison for men with complex health or disability needs which typically has a waiting list:

I didn't know anything about this unit when I first came into prison ... A lot of tension was taken away when I came up here because the facilities and care you receive are so good (Lived experience expert).⁵

Prisoners often have to be moved away from whānau to receive the care they need in Rimutaka.

Dying in prison is viewed by some as a 'double punishment'. For others, prison is a **safe environment**. Being in prison provides structure and support to have basic needs met, including regular food, warmth and security. The resulting institutionalisation of some people as they move in and out of prison can mean they are unable to consider the outside world as a safe home at the end of life.

That's a hard thing to break from our people, 'cause if they've been into jail like many times, backwards and forwards, and it's for really minor things. But that's all they know because outside's not helping them, they're not getting anywhere, you know? They're not coping with the outside, out here, but they cope in there 'cause everything's controlled, eh? They're used to that lifestyle (Service provider).²

Some people have spent so long in prison they no longer have ties to their community and are **estranged from family and whānau** as a result of their criminal activity.

He had no family and he saw us as family, whereas other people may be supported family-wise. They may benefit from being out of this place if possible. But he didn't have that. His was a little bit different from that because simply he had nobody, and we were it for him (Service provider).³

Close relationships can form between staff and prisoners, particularly for those who have been in prison for a long time. Death and dying can be **emotionally difficult for custodial staff** who have no health or palliative care-related training.

Compassionate release may be granted if the prisoner has a 'serious illness from which they are unlikely to recover'. To be eligible death must be likely within days or weeks but will not be granted for those deemed 'too dangerous' regardless of their medical condition or prognosis. The person must also have suitable accommodation available, as well as support from carers. However, many do not, particularly when they are estranged from family and whānau. Aged Residential Care facilities are also often unwilling to take people from prison based on prior offending and the reputational risk this may pose for the facility.

Finding accommodation is a big problem. Rest homes don't want them. [We have one prisoner with dementia who, because of his illness, is] becoming more challenging so rest homes won't take him (Service provider).⁵

Respectful, dignified, and caring palliative care is possible even in the current context of NZ prisons as outlined in a case study of a prisoner in a forensic mental health unit. He had been resident in the unit for 25 years when he was diagnosed with an incurable cancer. The staff worked with him to develop a bucket list.

The staff were absolutely wonderful to him, they took him out for breakfast once a week, he went to a rock and roll show, it was amazing, and they pulled out all the stops. He had a really good time in the last six months. He had had a crappy life and he would often just sit with me and talk about how kind people were (Service provider).³

However, as he deteriorated the staff found it **difficult to provide the necessary physical care** to keep him comfortable. They were not adequately resourced, or trained, to provide palliative care and eventually the man had to be transferred to the local hospital where he died.

A general practitioner's story

I worked as a doctor in the prisons for a long time. Most of my work was primary care stuff. It's the best access to medical care many of them have ever had. For the most part, they can fill out a form and within a few weeks see a doctor. That's often why, unfortunately, sometimes you're the first to pick up their cancer or their diabetes. Thankfully there wasn't too much end of life care, but it did come up from time to time.

I looked after a few older guys with COPD who couldn't get around. There were a few rooms with their own showers and toilets. Some had allowance for extra assistance to help them with showering and that. For the most part, they were still in there because of the level of crimes they had committed. Basically, if you get sick and you're frail, they do tend to get you somewhere else. You might get a compassionate release and you can go home, or you can go to a whānau member's house. But often, these were crimes that were too horrific, so they were not eligible for that, or they didn't have whānau who were willing to take them in, usually because it was offending against whānau. But end of the day, they're people, we're health professionals. They need care, so we look after them.

In prison they don't have easy access to certain medications because it's not like you can have a morphine pump on somebody in prison. If you're at home and you need painkillers, you get your box of pills and you can take them when you want them. Or your whānau who's looking after you can offer them to you. Because it's okay to have a box of morphine sitting around. Obviously, in prison there are restrictions. The morphine has to be given at set times. If it has to be three times a day, the nurse goes out to them three times a day. The prisons don't have a Registered Nurse on 24/7 so if they start needing more we try and get them out, but that's always a problem. Obviously, the hospice doesn't want prisoners there with prison officers, but often we can find a rest home that will take them.

Actually, dying in prison creates a lot of work for everyone. Even if it's an expected death like from cancer or COPD it freezes up the unit for the police to come and do their investigation, you have to write reports for the coroner. There's a good reason why every death in custody is a coroner's case. You want to make sure that they got the appropriate healthcare, so you have to do that. But the coroner's case holds up the [tūpāpaku](#) being released for the whānau. I mean, that's not just the Māori thing either, that's for anybody. Whereas if they pass away in a rest home, death certificate can just get done and the whānau can get on with their process.

It's terrible for their whānau if they can't be there to be with them in their last moments. I used to remind people that they are still somebody's son. Just providing better care in prisons won't fix everything because then if they pass away in prison, there's little chance for whānau to be involved.

Palliative Care for people Living in Rural Deprivation



Context

- Thirty nine percent of New Zealand’s land mass is considered rural.
- Twice as many people in rural areas experience social and economic deprivation, particularly in remote areas.
- Across all ethnic groups, there is a high rate of premature deaths that could potentially be avoided given effective and timely health care.
- People living in areas of deprivation are less likely to experience a hospital or hospice admission, or have contact with their general practitioner, in the last year of life. This inequity is amplified in rural remote settings.²
- Twenty five percent of the Māori population live in rural areas.

Contributors

- Jackie Robinson, Stella Black, Merryn Gott and Janine Wiles contributed to this section.
- The two stories were collected as part of the *Te Whakehekenga: Dying as a health and social justice issue* study, funded by the Health Research Council.

Josie's story

My mum was 93 when she died. She kept really good health for most of her life. She was so independent living alone in the big whānau homestead. One day she had to go to see the nurses at the clinic. I asked if she wanted me to go with her, but she said, "no, no...I'm all good". But she had a fall after I left. The nurses came, put her in a wheelchair and wheeled her to the doctor's surgery. They had a look at her and just sent her home, she didn't even get to see a doctor. No x-rays, no sending her to hospital to get her checked. When I went around later that day, we found a huge hunk of skin had peeled off her leg. When she fell, she must have ripped her skin, it was so fragile. The nurses didn't check her properly.

Mum just never came right after that. She had two more bad falls. She started saying she had a sore hip. She was black and blue all over. I tried to get hold of a doctor, but it was the weekend, and nobody was around. Whanau came and helped me, we gave her a massage to help relieve the pain. I kept leaving messages at the doctors, but nobody rang me back. Finally, I talked to the receptionist on Monday. I told her my mum has had a fall and I can't move her and she's in pain. Just bring her in, she said. How could I do that if I couldn't move her? So, she told me to dial 111 and get an ambulance but my mum didn't want to go to hospital. I asked her for more help, but they told me it was going to take two weeks! My mum was starting to have accidents, messing the bed. I ended up having to burn the sheets, I couldn't get them clean on my own. I started buying pads from the supermarket. When the doctor finally saw her, he said "Oh, I didn't realise it was so serious". I was so angry with that. I had been trying to tell them on the phone, but nobody listened.

The carers were great with mum, but the rules were stupid. I wasn't allowed to give the caregiver a cup of tea or give her food even when we were eating. In the end I just did it. I told her it was just between her and me. After she had put mum to bed we would eat together. That's when we got to talk and get to know each other.

In the end my mum ended up in an old people's home. I slept in a lazy boy beside her for two months. I felt I needed to stay to care for her and to make sure she wasn't neglected. Most of the nurses were great, sometimes they would invite me into their office, and we would share [kai](#). One time I brought in a crayfish to share with the nurses. When she had pain, they wanted to give her morphine, but it made her go doo doo la la. I refused the morphine and did [mirimiri](#) on her and the pain went away. Four weeks before mum died, she was retaining fluid and she got blisters on her arm, they popped, and they went very bad. I got my friend to make me a brew of [kopakopa](#) and I started rubbing it into mum's skin, rubbing it around. Within five days, it started to scab. The day mum passed away, the doctor came in. I know she believes in [rongoā](#) so I showed her too. I know she was impressed with what I had done.

The whole thing with my mum was really hard. I couldn't look after her at home on my own, but I stayed with her in the care home all the time. I had to be strong, and the worst thing is that my family were useless. If you're fighting with your family, it just eats you up inside. I had to find my happy place through that time, my garden was my happy place. I get on the verandah with my cup of tea, and I just look at my beautiful garden. All through that time nobody listened, but I know I took good care of my mum.

Evidence summary

People living in rural areas of deprivation face **lifelong challenges accessing healthcare**. This results in people presenting with **advanced illnesses at a much younger age**.

Here, we see people coming in with certain diagnosis, health conditions, being very, very advanced and at that kind of terminal phase, much younger than in town. I would see people here that you think you shouldn't be at this point for another 20 years, but their health is so compromised...Something is not equitable (Service provider).²

When health issues are not addressed in a timely way, or palliative care needs anticipated and planned for, **people are more likely to need emergency care**. However, in rural areas access to urgent care, particularly out of hours, is difficult.

We rung an ambulance at four o'clock in the morning and they said, "oh we don't run until about six o'clock." I was really angry because he was really in pain (Lived experience expert).²

However, there is evidence of service providers based in small rural communities going over and above what they are considered 'allowed to do' to fill gaps in care:

We've just got this lady living at home and her daughter's going back up North, so she's gonna be alone but the carers are stepping up and we're going above and beyond, and they'll be collecting her scripts for her, they will be cooking her meals, feeding her dogs, picking up the dog poo, and doing all that stuff (Service provider).²

Travel costs and distance to healthcare impedes access to services, particularly for those who already have limited financial resources.

It's even transport to go and see the GP, some whānau don't have money, petrol to go to the GP. They may not have petrol to go and pick up their prescriptions (Service provider).²

This compromises the quality of clinical care received:

Yeah, so his son couldn't visit. His wife was with him sometimes...there was a time his nasogastric tube had fallen out and he really needed it inserted so he could maybe gain some weight and have a little bit of treatment or something. But he didn't present for days because he didn't have someone to take him to the hospital, he needed his sister to take him in by car. So, there was just, everything revolved around transport and money, just the whole way through, and they had nothing (Service provider).²

Some rural communities have access to health-funded shuttle transport from home to appointments, but many are not aware of the service.

Palliative care relies heavily on family and whānau to support someone at home at the end of life. In rural communities, access to support for personal care is limited and family and whānau caregivers often fill the gaps that community-based services are unable to provide.

He always had a whānau member there, yeah to sit with him 24 hours a day, yeah even at night, someone was always there. So, they had shifts, you know which I made them do, hurry up, do a calendar, who's gonna be here? (Service provider).²

However, some **family and whānau are left to manage medications alone**, with many feeling unsupported and unconfident, particularly in administering morphine by injection.

I wasn't too confident in giving him his injections, so we gave [the responsibility] to my son. I said, I'm not confident in that, I might overdose him ... we did the other, bathing him and so forth and whatever he needed (Lived experience expert).²

The **financial burden** is significant if the ill person becomes too sick to work. Households often cannot afford for family and whānau to take time off to care:

Ideally someone has to be there for them. But then some of them, they have to keep working. They're like, I've got to go to work...they've got no option but to leave their loved one home alone because they need money, they need food (Service provider).²

Previous experiences of not receiving support when needed, often due to living remotely, leaves people **distrustful of the system**. This results in lower expectations of health services and a sense of resignation when they don't get what they have been promised.

I don't know. We only saw them once at the hospital. "Oh, we'll be over, we'll assist you". I went, "Yeah right". You know when you get those feelings... when they're from the health organiser and they say they'll come and awhi and tautoko the whānau and so forth (Lived experience expert).²

Access to general practitioners is challenging in rural communities. As one whānau shared, a lot of families or people who are from here and have come back to stay cannot get a doctor because it's full.²

Home visits from general practitioners are not always available; when they do occur this is out of a commitment to the community, rather than an expected service.

I think [rural communities] have always been resilient and resourceful. I also think that there's a lot of historical barriers to them accessing care, but the GPs up that way are staunch advocates for their people, and they ain't gonna hold back, which is great (Service provider).²

However, the **general practitioner shortage** and resulting workload creates barriers for practitioners to extend their role into providing palliative care.

There is the lack of GP coverage and a lack of GPs who want to engage more out in the community. They're just stretched and some just don't provide it (Lived experience expert).²

Many people living in rural remote areas are Māori. A lack of culturally safe care, along with experiences of racism within the healthcare system, leads to distrust in mainstream and palliative care services. For some whānau there is also a resignation about government commitment to support good healthcare in their communities.

We've got to also realise politically our little towns are the last ones to get doctors. We're always getting stand-ins, relievers, duh, duh, duh (Lived experience expert).²

Improving palliative care for people living in areas of rural deprivation is essential, but as one expert with lived experience put it: **Why do we have to wait till we're dying?**²

A nurse practitioner's story

After many years in a clinical setting, the biggest reflection I came to, was realising that when I saw all the residential addresses for patients I was seeing in a clinic room or on the ward – it went completely over my head. That was until I drove out to some of those places and saw for myself why some people were constantly coming back into hospital.

I got a referral to go out to see Kauri who had previously been admitted to hospital, several times over with infections, pneumonia, needing IV antibiotics. Kauri had cancer, lung disease, COPD and emphysema, and although he wasn't dying imminently, he was expected to have only a short time left. Kauri was surrounded by his whānau, they were staying with him and doing their best to care for him at home. They were doing really well despite the challenges to honour his wishes. Kauri had told his whānau that he didn't want to go back to hospital.

It was my first ever home visit and I had to use my GPS to get there because I didn't know where I was going. As I pulled into the driveway my first thought was, okay this must be the workshop or garage. It was a wooden timber framed building. I was looking around for the house but there were no pathways then I realised this was the house. As I stepped inside, I could feel that it was immediately damp and cold. I could see the wind was blowing the curtains around. The house was freezing cold, and everything was damp. In that moment, it all made sense. Kauri's respiratory infections and respiratory complaints were due to his living conditions.

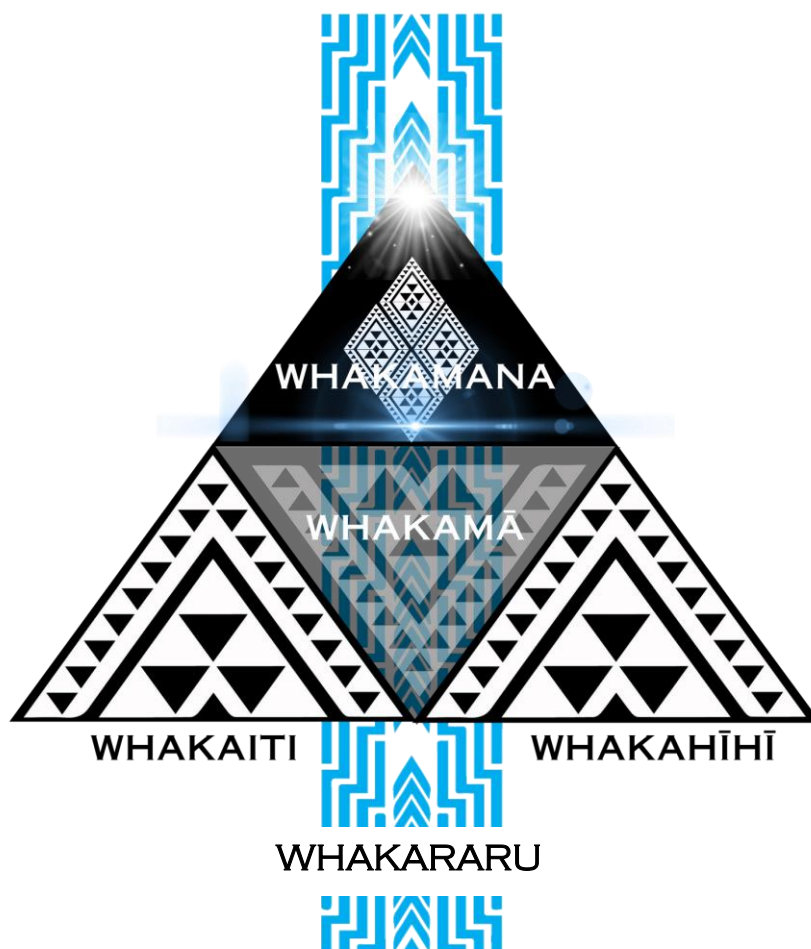
As I spoke with Kauri and his whānau, they told me he had developed a few more symptoms from the day before. I did a respiratory exam of his chest and heard he had been getting fevers that indicated he was having another infective exacerbation. I knew he didn't want to go back to hospital, but he urgently needed antibiotics to deal with the infection. I thought, starting him on antibiotics that day would be simple, but it wasn't.

The whānau said they could pay for the medication but because the pharmacy was 50 minutes away picking it up was the problem. A niece offered to use her uncle's car to go and get the antibiotics, but the car had no petrol in it. Another whānau member suggested they could phone someone else to help, but realised they didn't have credit on their phone. Then someone said one of the whānau is coming home soon, and perhaps they could phone someone who's in town to get the meds. So, what I thought would be relatively straight forward to get treatment for Kauri was proving almost impossible.

Eventually, we managed to get someone who was working in the main town centre. They got someone on the phone to send the prescription to a pharmacy in town, it was then picked up and dropped off so that Kauri could start his antibiotics straight away.

So, getting treatment just isn't that straightforward for some people because of that deprivation and socioeconomic inequity. The health burden and quality of life for people in this community is really worrying. Now, when I go to meetings, and you hear things like the social determinants of health and all these things get thrown around and I think a lot of it just makes us feel good because we're seeing this stuff in meetings. But then you go out and you're like, okay, now I've seen it, I've seen that this is actually real.

Palliative Care for Gang Affiliated/related Whānau



- The term gang is problematic because it perpetuates stigma and negative labelling.
- In NZ, inter-generational gang membership is established through gang affiliation and [whakapapa](#) connections, often over generations.
- There are more than 8,800 gang members from 33 different gangs in NZ, New Zealand.
- The Bay of Plenty region has the highest number of gang members, many of whom are Māori.
- Socio-economic deprivation is a significant predictor of gang membership which is related to a lack of opportunities to engage in education and employment and trauma related to abuse, including sexual abuse and social exclusion.
- Gang affiliated/related whānau have a high level of unmet physical and mental health needs.

Contributors

- Jackie Robinson, Stella Black and Merryn Gott contributed to this section.
- The stories were collected as part of the Te Whakehekenga: Dying as a health and social justice issue study, funded by the Health Research Council. Research presented in this section was conducted in partnership with Waiariki Whānau Mentoring.

Manu's story: He Manukura o tōna ao

Manu was a senior member of the local Mongrel Mob when he was diagnosed with incurable cancer. I had known the whānau for a long time having lived and worked as a nurse in the community for many years. Occasionally Manu would ring me to ask me questions about his medications. I think it was easy for him to ring me because he knew me. He managed to stay off alcohol and cigarettes for about 18 months, but found it hard to give up alcohol long-term. Drinking with his mates was an important social activity for Manu.

Manu remained heavily involved with gang activities as did his partner and their children. They were a very pōhara family so found travelling long distances every month to see the specialist liver team difficult. They also needed to pay for accommodation, petrol and kai for Manu and his whānau. They really struggled to navigate through all the medical stuff. There was no one really able to support them with that.

Manu was on home detention when he returned home from the hospital. He had been told by the doctors that time was short. He wanted to die at home, he didn't like being in hospital and actively resisted any support from services. So, when a hospice nurse turned up out of the blue one day at his home the whānau didn't appreciate it. They weren't aware the nurse was coming or that the hospital had referred Manu to hospice. I think the hospice nurse was intimidated by the patched members around the house. On that day, the hospice nurse gave Manu some morphine and the whānau thought she was trying to kill him. They rung me really upset and I went around straight away but the hospice nurse had already left – she never came back. Sometimes I wonder if the hospice nurse did try to explain what she was doing but maybe the whānau were focused on Manu and didn't understand what was being said. I don't know whether the hospice nurse tried to come back but after that I was on "speed dial".

The whānau were really good caring for Manu. They would do his cares and he was never left alone. They had a roster and did shifts, and everyone was willing to do that, spending time with Manu before he went. Even the members of the gang would come up and see their brother. They set up a space outside the house. Food was constantly flowing, but it was always within their own world. I just went in and did what I needed to do and left them to do what they needed to do. I answered their questions. They trusted me.

The calls from whānau got more frequent as Manu deteriorated, ringing me at night to make sure they were giving him the right medication. They were freaking out the day he died. I tried to get them to phone the hospice, but they still thought the nurse tried to kill their Dad. Walking alongside Manu and his whānau was a real privilege because they accepted me, and they trusted me. I walked along that journey for years with them, no judgement, just doing what needed to be done.

Evidence summary

Whānau have a high exposure to death and dying through violence, abuse, mental health and addiction.

I was a real violent man. Sneaky violent. What do you call it? Thought I was powerful... Anyone that was all in that negative space, I would squash them, yeah, (Lived experience expert).²

Underlying addiction and mental health issues are often associated with a lifetime of trauma, violence and abuse:

It's like peeling an onion layer upon layer... So, what's appears to be an addiction issue is actually a systemic level of abuse where they have been harmed physical, sexually and psychologically (Service provider).⁶

Experiences of systemic abuse and trauma can lead to mistrust in organisational based services such as health and palliative care services:

They really mistrust...because they've been let down a lot, so they don't really engage much with organisations... People say that they're gonna do something, and then they don't. And then they're being judged at the same time (Service Provider).²

Trust takes time to establish and is an important factor in staying connected and engaged with healthcare professionals. The gang environment can be different to what many health care professionals are used to.

...so when he [the gang member] got discharged, hospice turned up, but the family weren't aware of the plan, or they didn't understand the plan. So, when this hospice nurse showed up, I think she was intimidated (Service provider).²

Working with organisations who already have the relationships is key.

If we can change those behaviours from within, we'll see the transformation that's required. But that only comes with trust (Service Provider).⁶

Understanding people's lived experience, and not judging, is an important part of being able to establish authentic engagement.

Because I've been on and off the meth for about half my life now, I've been to counselling and I always say to the counsellors, have you ever tried it? And they'd say no and then it's like well what's the point in talking? So I'd just tell them what they want to hear (Lived experience expert).⁶

Health is prioritised by whānau. However, they struggle to connect with healthcare services which partly relates to practical barriers, such as access to money.

I won't go to the doctors unless I'm bloody dying, 'cause I don't wanna pay, you know 15 bucks [and] for the most part, it's a day or two for the appointment. But, I need the appointment next week. Because my payday's next week so I won't be able to pay that bill (Lived experience expert).²

Internal barriers such as feeling different or not good enough can make it difficult for whānau to advocate for themselves. These are compounded by assumptions and judgements made by healthcare professionals based on physical appearance:

J was at a GP clinic, full face tattoos, you know, Black Power tattoos all over his face, the doctors didn't even wanna see him. And all he wanted was just his foot looked at (Service provider).²

Many whānau disengage with health services because of past experiences, which will impact how they engage with services that provide palliative care. An additional barrier for Māori whānau is the disconnect between Western medicine and te ao Māori health models:

GPs are a big one. And a lot of that's around the way that they've been treated previously in the system. I think there's a huge mistrust there. If you look at how Māori culture used to be as well, and we look back to how it used to be. If you heard voices, then you could connect with people that had gone before you, then it's a gift isn't it. And it's not something you can medicate to get rid of it (Service Provider).²

Creating safe spaces within healthcare settings is important to achieving authentic and trusting relationships with healthcare professionals.

If there's something that I'm uncomfortable with, I won't do. But being here, I felt comfortable here. I felt I could talk in this space, be heard, be understood, and I wouldn't feel like, oh, shucks, you know, I've said the wrong thing, I've said too much, and I was fine (Lived experience expert).⁶

Whānau often prefer to be cared for at home in their own environment, with no risk of being judged by others while being supported by people they trust.

Because they were a very closed off whānau, they wouldn't, yeah, yeah they wouldn't let just anyone come onto their property, as well as the last name is a well-known name... And it comes with a lot of negativity, yeah, that they're not a very well-liked whānau. But that still shouldn't stop someone from getting good care, access to good healthcare (Service Provider).²

Service fragmentation and complex referral processes can create delays in receiving a timely diagnosis, including of a life-limiting illness. Often whānau present with advanced disease and in acute distress:

If you don't move quick smart, one, you lose the opportunity, but it could also mean death in this space. Because the triage process, in terms of those organisations coming into support, is too slow...we need a quicker response. Our whānau need that because we're working with acute and chronic disorders and addictions (Service provider with lived experience).⁶

A support worker's story

People won't connect with us about their health if they don't trust us, or if they don't know us. As whānau begin to trust they begin to divulge their previous trauma. Being raped as a three-year-old, being sexually molested, physically abused or being a child of a one-night stand that has left gaps in their sense of identity and belonging. Our whānau have also often had terrible experiences trying to access support or assistance from organisations and agencies. Many of these agencies have burnt our whānau. There is little to no trust, some whānau have experienced being judged, persecuted, disrespected, embarrassed, and are sometimes too ashamed to ask for help. Some would rather go without than ask for help. But are forced to compromise for the sake of their [moko](#) and [tamariki](#).

I know our whānau can get aggro but when you look at the life they have had over so many years, with so much trauma, then you can approach them in a different way with more compassion. But working on getting them to trust you is key, and that takes time. Some of our [hapori](#) have a strong gang presence and to be honest, we couldn't do our jobs without the gang [Rangatira](#). They help us build strong relationships with whānau who otherwise wouldn't engage with health services. Sometimes we just walk into these homes blind and not knowing what we're gonna come across. They might tell us their story and then still not want our help.

Housing is a big problem here; no rentals and emergency housing is a horrible environment. When whānau connect with our colleagues about housing, sometimes we also get to talk to them about their health. It's the same when they are working with our mental health and addictions colleagues, health is part and parcel of all these needs. We take opportunities to connect with whānau where and when we can. Whānau don't want to talk about their health if they don't have a house or are struggling with drug or alcohol abuse or don't have money for kai.

We have to be flexible and just do what needs to be done. Sometimes its listening to whānau without judgment, or helping them get kai, clean the house or whatever they need at that time. We need to build trust before we can ask them about their health. We help them create a care plan using the four pillars of Te Whare Tapa Wha. We provide care across the life span from [pēpi](#) to [kaumātua](#) and to all whānau.

But many of our gang [tāne](#) are not getting to the palliative stage, many die young. Either becoming seriously ill or dying from a heart attack as young men, just dropping off without that end of life period happening. So, we might begin with one whānau member and end up seeing the rest of the whānau. Sometimes they are open to it, sometimes they are not, and we respect that right. We have to just be there for when they are ready to trust us, no judgement and always with aroha and kindness.

Palliative Care for Rainbow Communities



Context

- Rainbow is an umbrella term describing people whose sexual orientation, gender identity, gender expression or sex characteristics differ from majority, binary norms. This includes people who identify with terms like takatāpui, lesbian, gay, bisexual, intersex, transgender, queer, non-binary or MVPFAFF+.
- Not all people with non-majority identities or expressions will consider themselves members of Rainbow Communities.
- It's estimated that people under the rainbow umbrella make up between 6 and 15% of the population.
- 79% of trans and non-binary people in NZ had thought about suicide at some point in their lives; for disabled people this skyrocketed to 91%.⁷

Contributors

- Lisa Williams, Tess Moeke-Maxwell, Julia Slark and Merryn Gott contributed to this section.
- The lived experience expert story is from the palliative care and end of life needs, of Māori and non-Māori older LGBTQI+ adults study funded by the Health Research Council and the University of Auckland.
- The service provider story is a composite story composed of several individual's stories led by Merryn Gott.

Jack's story

Much of my experience as a trans man navigating the health system in New Zealand has fallen somewhere between awkward and discriminatory. I've had many interactions that have been far from affirming. People rarely have bad intentions, however the fact that queer people exist often has not been factored into the approach. Intention ultimately doesn't equal impact, and some of these experiences have had me thinking about how many people could fall through the cracks and avoid the health system as a result. I'm fortunate I am in a position to support and advocate for myself, but it should not be this hard.

Being required to go to a Women's hospital when you are a guy is uncomfortable for all involved. I was asked by a receptionist while in the waiting room there if I was with someone (meaning a partner or family member). I went up to the desk to quietly let them know I was there to see the gynaecologist personally. The receptionist said something to the effect of "ohh – you're that one". It makes me laugh now to think about it - but at the time I felt very embarrassed and wished I could have seen the doctor in a neutral setting. My experience with that service proved to be highly traumatic due to a treatment injury I received from my surgery. I am still dealing with the implications of this years later, with numerous subsequent uncomfortable interactions in the health system to try and get the further surgery I needed to repair it. I had less than 48 hours' notice for the surgery after being on the wait list for over a year beforehand. When things went wrong, the surgeon's attitude was that he thought I'd be grateful because no trans people were getting surgery in the public system at the time. I was lucky?

I'm acutely aware that making it into old age isn't a given for many trans people. It is difficult for me to imagine. I am quite scared about being in a vulnerable position where I can't advocate for myself and am reliant on others caring for me. Will I be outed and treated like a freak? I hope not. And I hope that isn't happening to people out there now.

It is critical that all health services, including palliative care, expect this diversity in the community and plan for it. It isn't about 'special treatment' for rainbow communities – it's about ensuring basic health needs are met without barriers and being treated with dignity. When you are in a vulnerable state you need to feel safe and respected for who you are. Palliative care services may benefit from having general guidance on how to care for rainbow people in an affirming way, especially if they are not able to advocate for themselves and their family has different ideas (eg name, pronouns). It is important that individual privacy is upheld, with information about someone's LGBTIQI+ status only shared where relevant to those directly involved in their care.

Evidence summary

Members of Rainbow Communities often experience **late diagnoses of a life-limiting illness**. Not understanding the health issues relevant to Rainbow Communities can affect a timely diagnosis.

I went to my doctor and I said I feel like shit and he said oh you've got that flu, and I said I am really weak and he said "oh well take a week and relax"..... I went and saw the gay doctor and he said "you have got hepatitis" and I did, I had Hepatitis A but my doctor didn't think of that because his client base isn't gay men who are at risk of catching hepatitis and AIDS [...]] (Lived experience expert).⁸

Trans and non-binary people experience **barriers to cancer screening**. For example, many delay cervical and breast screening, attributing their delay to concerns about how they would be treated as a trans or non-binary person. These concerns are often linked to **previous experiences of discrimination** during healthcare interactions:

Even when I have concerns related to genitals or 'private' areas I have a huge amount of anxiety about asking a ... health professional about it. A few times I have eventually forced myself to get care and treatment but found the experiences quite traumatic and am back to avoiding getting care (Lived experience expert).⁹

Institutional care, including Aged Care and hospital care, often feels unsafe for trans and non-binary people due to transphobic attitudes on the part of both staff, patients and visitors. One trans woman in her 80s shared her experience of verbal abuse by a cis gendered woman in the adjacent hospital bed next to her:

*She said I'm not staying next to a f***** transgender person. She was then put at the other end of the room, but the abuse didn't stop. When I had visitors the women would loudly point out that I am a transsexual. She was very unkind (Lived experience expert).¹⁰*

Health professionals often assume a same gender partner is a sibling or friend. This can impact the level of support they receive. Unmarried same gender partners, and other family of choice with no recognised legal status, can also struggle to be heard when conveying the **end of life wishes** of the person they are supporting.

Me and my partner regularly get mistaken for being sisters, which is really embarrassing both for us and for the health professional. We've been civil partners for decades, but that didn't include next of kin status which made us worry about what would happen if one of us was seriously unwell. We got married to make our choices regarding care more secure (Lived experience expert).¹¹

Navigating the use of single sex bathrooms can create significant stress for trans and non-binary people. Those on **hormone treatment** also fear this will be stopped without their consent in institutional settings, particularly if they are not able to advocate for themselves. Without hormone treatment people can feel as though they are "slowly dying" (Lived experience expert).¹⁰ It is therefore unsurprising that **trans and non-binary people would typically prefer to receive end of life care at home**.

There is a need to recognise the **intersecting identities of members of Rainbow Communities**. For example, racism for Māori can be a more significant negative influence on their healthcare interactions than their sexual or gender identity. Age is also important, with many **older members** of Rainbow Communities having experienced forced, highly traumatic, **conversion therapies** in their youth which continue to impact their healthcare experiences.

In the health system, with their issues, they treated it as addiction. I was committed to [psychiatric institution] (Lived experience expert).¹⁰

Members of the Rainbow Communities **experience higher rates of mental health problems** than the rest of the population. The psychological distress encountered as someone nears the end of their life can add a high degree of complex palliative care need for Rainbow Communities.

Being trans isn't something that that causes mental distress or harm. It's how the world around you treats you for being trans that does the harm (Lived experience expert).⁷

Levels of grief, particularly in the trans and non-binary community are high. This also impacts service providers, many of whom are community members themselves. **Working to relieve suffering related to death and bereavement** is a core part of their role:

Palliative care is something our community is doing all the time...we just don't call it that (Service provider and lived experience expert).¹²

Rainbow Communities know what is needed to improve their healthcare experience, including experiences of palliative care. They want health providers **to use inclusive language** and create safe spaces for them to disclose their sexual and gender and identities if they wish to.

Make sure you know who you are dealing with...don't make assumptions (Lived experience expert).¹⁰

Using language which is congruent with a person's self-defined identity is particularly important at end of life when people may be unable to advocate for themselves and their biological family may not be accepting of their identity. Service provider organisations need to develop systems to collect information about gender identity and sexual orientation, where this is relevant to a person's care. **These systems should be designed with the input of lived experience experts** and recognise that language changes quickly in this space:

What best practice is now won't be best practice in the future so we have to be flexible and our systems need to be flexible (Service provider and lived experience expert).¹²

A nurse practitioner's story

Lots of people think that when gay marriage was legalised, discrimination ended for our community. If only it were that simple. Things are certainly better. My older patients remember the days before Homosexual Law Reform. But it's that assumption that you are heterosexual and cis-gender that persists. For example, my girlfriend was in hospital recently. I was sat by her bed for three days before someone asked if I was her partner. And obviously that nurse was gay himself.

I worry in particular about our trans community. They face a lot of prejudice. And ignorance, even in healthcare spaces. One of my patients was taken off her hormones without consultation after her stroke. She took the issue to the Health and Disabilities Commission and won her case. However, she still felt let down as they have no powers of enforcement.

I think another issue is that people often have to out themselves to get the care they need. But as health professionals we should approach every interaction thinking maybe this person is trans, maybe this person is gay, maybe this person is inter-sex. And educate ourselves about what that might mean for the care they need. Not put that burden on to the patient. That's my job as a nurse. To not presume anyone is anything like me. Or not like me. And most of all, to not judge.

Using inclusive language is so important. That doesn't make assumptions. Something as simple as "Can I check which pronouns you use, mine are she/her?" can make a big difference. You need to give people the opportunity to choose the language they use to describe themselves. Because this varies. My older patients use quite different language to my younger ones. You also need to signal that you are safe, your healthcare space is safe. It's certainly not just about putting rainbows everywhere, but that helps.

Death is something we deal with constantly in the Rainbow Community. Suicide rates are much higher than they should be, particularly in the trans community. If someone rings rather than texts my first thought is "who's died now?" There's a lot of complicated grief.

When it comes to the end of life, feeling safe is everything. And unfortunately, many in our trans community in particular will never feel safe in an institutional setting. They want to be at home where they have control. And they are right to be wary. I've heard of older people being taken off hormone treatment in Aged Care by their families when they are cognitively not able to request it. So being at home, having a plan around who will support you to use your hormones, who will support you with intimate care. Being able to use your own bathroom. Having the family you have chosen around you. These things are so important.

Palliative Care for Refugee Communities



Context

- Every year, around 2,500 refugees arrive in New Zealand seeking a better and safer life.
- Refugees enter NZ through three main streams: refugee quota, protection claims and family support.
- There are 12 refugee settlement locations around NZ.
- Studies exploring experiences of NZ healthcare included people from Afghanistan, Myanmar, Somalia, Syria, Eritrea, Thailand, Iran, Iraq, Saudi Arabia, South Africa, Nepal, Bhutan, Uganda, Sudan, Rwanda, Colombia, Cambodia, Laos, Chile, and Fiji.

Contributors

- Ruth Choi Lee, Maryam Pirouzi, Jay Marlowe, Jackie Robinson and Merryn Gott contributed to this section.
- The stories are composite stories comprised of several individuals' stories gathered during consultation for this report led by Ruth Choi Lee.

Naung's story

Safety and a sense of security are vital for us with refugee backgrounds. I arrived in New Zealand through the United Nations refugee quota programme. I left my country for my own, my husband's and my children's safety. Leaving where I built my family and community was sad, but it was no longer safe for us. At first, we stayed in the Māngere refugee settlement centre. I had a health checkup, which I haven't been able to have in the past few years. I found out that I have diabetes and liver failure. It was the first time I knew I had a health problem. We had been living in survival mode, and health checkups are not a priority when you are fighting for your lives.

Some of us find it really hard to access a general practitioner. One of the barriers is the cost – it is expensive. Language is another barrier- it is incredibly challenging to find a GP practice that provides interpreters. We are not fluent in English. Today, when I went to the GP, the phone interpreting service was booked but then was suddenly unavailable. I started to doubt whether it was booked in the first place. I am having mistrust. They call my son, who is studying at university. He is much better in English, so he gets these calls and is our family's unofficial interpreter. I am thankful that he can, but I wish not to discuss my health issues with him especially since my diabetes and liver failure seem to be quite serious.

I had to go to the GP multiple times. I felt like it slowed down my access to a specialist. Back in my country, I would be able to go to the specialist straight away. So, I went to the hospital myself. There were male nurses and health care assistants. I feel very uncomfortable with this. Can I voice this? Will they discriminate because of my background? As a female I am embarrassed being cared for by the male practitioners.

I met the palliative care team today. This is such a shock - what does this mean? Palliative care is very foreign to us. We thought it was only for the very end of life and only for cancer patients. My family want to care for me at home. I want to be in the security of my family. It's important to feel safe after all the adversity I have faced being a refugee. My people feel it is the family's duty to care for their family, so accepting palliative care means the family are neglecting the patient and not doing their duty.

The language and the way diagnoses get delivered here are very direct. Back home, we don't have access to the health system like the people here. Because everything costs. So, when someone has a terminal illness, the medical team will say, "You can go home to your family", or "Time is getting closer", and it is up to the family to care for them at home without health professionals' further input. So, this palliative care approach is all so foreign.

Evidence summary

Language and communication barriers can leave some refugees feeling helpless as they try to convey health concerns to healthcare providers.

When we try to make an appointment by calling a receptionist, sometimes we struggle to understand each other and then the receptionist hang up the phone. This has happened to me. Some of them get angry when they cannot understand what we say (Lived experience expert).¹³

Relying on interpreters is challenging for many refugees. **Access to interpreters** is unpredictable across different health services. The quality and acceptability of the interpretation service is inconsistent, and many refugees raise concerns about privacy when using formal or informal interpreters. This has **particular implications when issues being discussed are highly sensitive** as is the case for palliative care:

Because it's such a small community here, there's a high chance that you know that interpreter. And if it's a personal thing, you're not gonna want that person there. Yeah. So like, and one of the ladies here, she never takes an interpreter with her. I always go with her because she doesn't feel comfortable with sharing whatever she wants to share with the interpreter. Because she's like, I will know that person. And I don't know how confidential they will be (Lived experience expert).¹⁴

People from refugee communities report feeling like **second-class citizens** during healthcare interactions. When they share previous healthcare experiences from their home country, people report being told "This is not ...(country), and you can go there if you wish to access that", (Lived experience expert)¹⁵. These negative experiences lead to mistrust and a lack of safety. "Safety and a sense of security are vital for us with refugee backgrounds", (Lived experience expert)¹⁵ and can be developed when health professionals take time to listen:

They just ask and we accept ... I'm okay with anything they [HCPs] told me. So, we trust the government, we trust everything. Whatever they say it, we are okay with that" (Lived experience expert).¹⁶

Expectations that healthcare should be solely focused on treating the illness rather than managing the symptoms such as pain can be interpreted by refugees as meaning that they are **not being prioritised or valued** by health care professionals.

We don't work, we don't pay tax, that's why they are treating us like that. That's the answer we [come up with] when we are in the community. [We] don't pay tax. The Government cares only [for those] who pay tax. So that's why they [doctors] only give us a painkiller. Why [waste] my money and my time, and at the end you give me a painkiller. And you say to me, drink water. They don't [even] check (Lived experience expert).¹⁶

Navigating through the fragmented healthcare system proves to be another daunting task. Long waiting times, short appointment slots, and bureaucratic barriers often leave people feeling overwhelmed and frustrated. This is particularly burdensome when people have palliative care needs:

Here [in NZ], if something happens to you.... even if you die, you have to make an appointment! Or for example, if you go to Emergency, we have to wait for ages that you say okay prefer to die at home but not here (Lived experience expert).¹⁶

Experiences leave many from refugee communities with **"very little trust in the NZ health system"** (Lived experience expert).¹⁵ The need for palliative care can be perceived as another

way of healthcare professionals withholding treatment for the illness. Palliative care may be seen as a failure of the health system to ensure timely diagnosis and treatment:

It does not matter how much good care is offered at the end. It's a failure already (Service provider and lived experience expert).¹⁵

Healthcare professionals experience challenges in providing care for refugee communities within the constraints of the healthcare system. For example, current models of general practice pose challenges to addressing the **complexity of health and social care needs people experience, particularly at the end of life.**

They have got so many problems, they have got diabetes, they have got respiratory problems, they have got sight problems, they need home help . . . With dealing with all of that there is another part of me that kind of forgets about everything that comes from their culture because you got such a short time, and there is so much to deal with . . . it does become very difficult (Service provider).¹³

Refugee communities know what they need from health services. Religious communities that they feel connected with are a significant source of support at the end of life. Caring for their own family in the way that they feel is best from a spiritual and cultural perspectives is important; “he/she won’t get the care we could give at a care setting” (Lived experience expert).¹²

Often, many of us need to have prayers five times a day, which needs cleansing of the body beforehand. We know the carers cannot provide this, and we don't expect them to do it either. But family can do this, so we keep families at home (Lived experience expert).¹⁵

Being at home enables refugee communities to provide an end of life environment which is familiar and supportive. At home people are not questioned or have to explain the practices that are so vital to their comfort and belonging.

Prayers are vital, and religion and our religious communities are critical. Sometimes, they become our family and support each other. Music is a big part of us, too- playing our own cultural music will add a lot to caring for our spirituality. We eat our own food instead of the hospital food served here. These little practices go a long way and make a difference (Lived experience expert).¹⁵

Cultural sensitivity and openness to the unique experiences of refugees fosters a relationship which contributes to more equitable health outcomes.

It's no good saying: "I'll just treat them like anybody else" ... That's not what equity and justice are all about. You've actually got to recognise that refugees need to be treated differently because otherwise, you will not meet their needs, and that's part of cultural competency (Service provider).¹⁷

A support worker's story

Getting the hang of how healthcare works here can be overwhelming for some refugees. Places like the Mangere Refugee Resettlement Centre try to help by giving out info on how to access healthcare, but there's still a need for more support. And the support needs to continue after refugees settle into their new home too. There are big differences in the healthcare systems people are used to in their home countries compared to what they find here in New Zealand. It's especially difficult for people who have just arrived. I think sometimes their expectations are that New Zealand will have this amazing healthcare system and then they realise we have problems here too. Things like a long wait for appointments and tests can be a major letdown, especially if you're used to things moving faster in your home country. Some refugee groups are used to going straight to emergency rooms instead of going to a general practitioner.

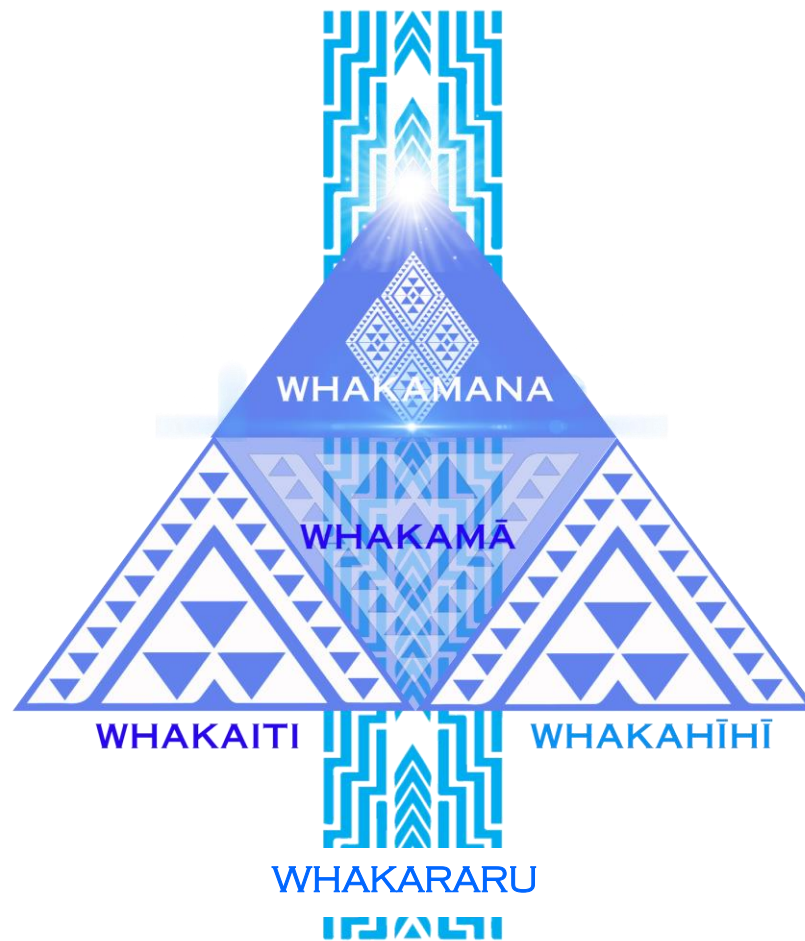
It's really important for healthcare providers to respect different cultures and give people space to have a voice. This is especially important for communities that place a lot of value on family and community ties. This is crucial not just for everyday care but also for services like palliative care, where it's important to respect cultural practices and individual wishes at the end of life. For individuals dealing with post-traumatic stress disorder, which is common in refugee communities, feeling safe and supported is everything. Building trust and providing an environment where people feel safe is very important.

Where people live can be a big factor for refugee communities. Living in a city like Auckland or a small town makes a significant difference. I think that's why you often see refugee communities gravitating towards bigger cities. In larger cities people can find their community. Finding people who have had similar life experiences and may have come from the same home country. This sense of belonging is important in people feeling more supported. It's understandable that being able to relate to people who think like you, and to whom you don't have to explain yourself is comforting. Also, if someone is nearing the end of life, the community might rally to support the person, even if they are not a family member. So being close to their community is a big support. Some of the smaller towns around NZ don't have these larger refugee communities. Therefore, where people end up living affects their experiences of health and palliative care.

Some refugee communities don't understand or have never heard of the word palliative care. Many communities are focused on curing illnesses. There are lots of myths and perceptions which might not be accurate, some of these may be based around their cultural values and beliefs about death and dying. Some people might see palliative care as giving up and don't know the possible benefits of receiving it. Even with service providers of refugee communities, there is not much talk about palliative care.

Trust is critical in supporting refugee communities. Without trust supporting people from refugee backgrounds is difficult. With trust will come an invitation to walk alongside people and give them the support they need.

Palliative Care for people with Serious Mental Illnesses



Context

- Serious mental illness is a term used to describe a grouping of diagnosed conditions related to the experience of enduring mental distress including schizophrenia, bipolar disorder, depression and personality disorder.
- People with serious mental illness are more likely than the remainder of the population to experience a wide range of physical health issues.
- People with serious mental health issues have two-to-three times the risk of dying before the age of 65 compared to the general population. Two-thirds of this risk is due to preventable and treatable physical illnesses.
- Often unrecognised is the intersection of ethnicity, mental health, addiction and physical health, with the largest inequities for Māori and Pacific peoples living with mental health and addiction issues.

Contributors

- Helen Butler, Jackie Robinson and Merryn Gott contributed to this section.
- The two stories were gathered during consultation for this report led by Helen Butler.

Graham's story

My brother Graham was three years older than me. When he was 15, he started acting oddly, wearing black, spending time in his room and talking to himself. I remember my parents were so concerned about him. Graham ended up being admitted to a psychiatric hospital when he was 16. I only visited him once in there. I could hardly recognise him. In fact, that is probably when I lost my brother.

After being discharged from that place, Graham became transient. Sometimes he was just living on the streets. One time he took off to one of the islands out of the city to escape from mental health services. He hated being on the medication – he said it made him like a zombie. I used to see Graham as much as I could. I worried about him all the time and felt responsible for him after Mum and Dad died.

One day I started noticing that he was coughing a lot, and he was looking really thin. I took him to see his GP. The GP and a few of the practice nurses were the only constant medical people in Graham's life and my brother trusted them. They listened to him and had the time for him. Even when I went with Graham, they focused on him and directed questions to him. He had some tests and then we were told he had cancer.

The cancer doctor took one look at my brother and pretty much said there was nothing he could do. He referred Graham to palliative care, but Graham didn't want to see them. They visited once, but didn't come back again. My brother continued to get worse – he was getting a lot of pain. He was living in supported accommodation by then and he just looked haggard. We kept seeing the GP and he did the best he could, but my brother was definitely suffering. He was admitted to hospital a few times, but they didn't seem to do much to help him.

In the end the supported accommodation people felt they couldn't care for him anymore, so he ended up in a rest home. He was 50 and in a rest home – I felt so guilty, but I am married with young kids, and I couldn't have him living with us. I visited him, but he hated it there, and he was no longer under the care of the GP – pretty much the only medical person my brother trusted. He played up a lot – he refused to take medications and became quite angry with the staff. This went on for months until he deteriorated enough that he just lost the energy to fight. He then stayed pretty much in his bed and died a few days after they put him on the morphine drip.

There were times when he was suffering, so I don't think he had a good death. It could have been so much better. The rest home staff really tried their best. If only the GP had been able to continue to care for my brother – maybe with support from palliative care. Maybe I could have had him home with me if there were supports in place to care for him. I just didn't know what services were out there and anyway Graham took a long time to trust medical people – he had been hurt by nurses and doctors over the years.

Evidence summary

People with mental health and addiction problems are treated differently in the healthcare system. **Diagnostic overshadowing** occurs when physical symptoms are explained away by co-existing mental health problems leaving people feeling frustrated and ignored.

My GP often tries to blame any physical problem I have on my anxiety. I know my own anxiety pretty well now, I know what it feels like and how it behaves. It frustrates me when my GP is not willing to investigate my symptoms and just says “it could be your anxiety” (Lived experience expert).¹⁸

Focusing first on pre-existing mental health issues can lead to healthcare professionals not seeing the person at all, instead they become **just the mental health diagnosis**.

I’ve got some people who have, you know, chronic mental health problems like, say, schizophrenia and I do tend—my default setting is to interpret everything that goes wrong with them in the light of their schizophrenia...they’ve got to work quite hard to convince me that anything that happens to them is not to do with it...You start seeing them—this is a schizophrenic, that is what it is—there’s no longer a person or a patient or a biological specimen—here’s a schizophrenic, you know? You can get into that way of thinking (Service provider).¹⁹

Ignoring people as experts in their own health and having physical symptoms ignored or explained away by pre-existing mental health conditions can lead to **late diagnoses of serious physical illnesses**. In addition, experiences of discrimination can lead to inadequate pain management which is concerning in the context of palliative care need.

In the last five years I have been struggling to get a diagnosis and get treatment for on-going pelvic and back pain as a result of adenomyosis, a pars defect [a stress fracture of the bones of the lower spine] and a few other factors. My mental health would be brought up in every appointment and often blamed for my inability to control my pain levels. [This was] despite already seeing a psychologist and psychiatrist, being on medication, and being in decent control of my mental health (Lived experience expert).¹⁸

Making decisions about preferences for treatment and care at the end of life is an important element of good palliative care. However, people with serious mental illness are often **assumed to be unable to make decisions** about their own health:

There is an assumption that [tangata whaiora](#) can’t make decisions. They often don’t get the information they need, for example treatment options or possible side effects. Decisions are often made without consulting them. This has often happened all their lives (Peer support worker and lived experience expert).²⁰

A **lack of health care professional knowledge and confidence** in supporting people at the end of life who also have a history of serious mental health issues results in barriers to accessing timely and appropriate palliative care.

When I was working in specialist palliative care, colleagues were very concerned about seeing any clients who had mental health or addiction diagnoses (Service provider).²⁰

People experience **stigma and judgement** by healthcare professionals and assumptions are made based on their mental health history and even the medications they are taking. Experiences of judgement and discrimination can lead to people not disclosing important information about their health. Assumptions about ‘drug seeking behaviour’ by health care professionals can lead to inadequate pain management, which has particular implications at the end of life.

I'm on a controlled drug for ADHD and feel that often I am treated as a criminal and a drug seeker both by my GP service and my regular pharmacy. Makes me loath to disclose any issue with pain or my anxiety as I know they will judge it as drug seeking behaviour (Lived experience expert).¹⁸

Accessing health care can be challenging, especially **when people do not feel welcomed** into the health space. Being judged for looking different or behaving differently is traumatic.

There are challenges for people with mental illness trying to access a GP clinic or even ED. Tangata whaiora often don't feel welcome in these places, often because we look different or act different. We get stared at a lot. We often get asked to wait outside. The receptionist and/or practice nurses are often gate keepers to getting care (Lived experience expert).²

Such experiences can stop people from seeking treatment, as can past experiences of **not being believed by healthcare professionals** or feeling judged by people working in the healthcare setting. This can result in **disengagement and distrust** in institutions leading to late presentations when things become acute or life threatening.

I generally don't seek help or I wait until something is really serious because I'm worried [healthcare providers] think I'm making it up or that it's to do with my mental health (Lived experience expert).¹⁸

As soon as they see my diagnosis of borderline personality disorder and history of addiction they would treat me as if I was problematic and an attention seeker, which ... has always stopped me from going to ED (Lived experience expert).¹⁸

People with a serious mental health issue often have a **significant level of complex palliative care need** at the end of life. In addition, they need time to develop trusting relationships. However, the time limitations of medical appointments are not conducive to meeting this level of need.

Short consultation times are not conducive to effectively caring for people with multiple physical health problems and/or when someone has both physical and mental health problems (Service provider).²⁰

A nurse's story

We have had people in our inpatient mental health unit who are dying, mainly in the older adult unit. Sometimes the death is expected, sometimes it is not. We have also had a few tangata whaiora who have died in the acute adult inpatient unit. When death occurs in the acute unit, the police treat it like a crime scene even if it is an expected death. If people are being cared for under the mental health act, there will also be a coroner's case.

We really try hard to make sure that the person and family and whānau are cared for well, managing their symptoms and make sure they are not in pain. The reality is that this doesn't always happen. Some of the psychiatrists are really good at referring to other specialists and prescribing good pain relief. However, I have worked with some psychiatrists who are really hesitant to refer to their specialist colleagues when physical health problems are detected. Instead, they will refer back to the GP to follow up which makes everything take longer. It also often means that the person has to meet another health professional – which is unnecessary if referred straight to a specialist – and extra cost for the person too. I have also noticed that psychiatrists are reluctant to refer to specialist palliative care like hospice. Often the feeling is 'they are not ready for that care yet'. And when they do refer to specialist palliative care, the psychiatrists are not always comfortable to prescribe opioids at sufficient doses to relieve pain. I think some see opioids as bringing about death faster. I have even had psychiatrists talk to me about the Hippocratic oath – their role is to save life and not to end it. So, they will often not prescribe sufficient pain relief and are often reluctant to prescribe sedation. We don't regularly use these medications in mental health.

It's really hard for mental health nurses who often feel stuck as they see the tangata whaiora they are working with in pain or experiencing distressing symptoms. I think mental health nurses feel they don't have the skills or knowledge around palliative care to advocate more strongly to the psychiatrists about what is needed either.

It's also really difficult to decide whether someone is not for resuscitation even if they have an incurable illness. It is even more difficult when someone is under the mental health act, particularly when there is no whānau or family support, or someone to help like an EPOA to advocate for them. Psychiatrists are hesitant to make decisions about resuscitation. I think this is because the mental health system is mostly focused on saving life and we avoid any risk around early death. We spend a lot of time trying to understand when someone is voicing a wish to die; are they suicidal or do they feel like this because they are depressed? That's what we do. So, when someone is dying from a physical illness it's challenging. Mental health nurses are good at discussing suicidality with tangata whaiora, but there isn't much training about how to have these discussions with someone who also has a physical illness. It's confusing for staff. How do you talk to someone about hope when they are dying?

Palliative Care for people with a Learning Disability



Context

- The terms intellectual disability and learning disability are used interchangeably; however, consumer advocate organisation People First NZ – Ngā Tāngata Tuatahi – have a preference for the term 'learning disability'.
- Learning disability is not the same as learning difficulty.
- Two percent of the NZ population has a learning disability.

People with learning disabilities:

- Die younger and experience higher rates of avoidable health conditions and deaths.
- Experience complex and multiple health conditions, with higher rates of epilepsy, respiratory and heart diseases, diabetes, cancer, dementia and mental health conditions than the remainder of the population.
- Experience access challenges and discrimination within the health system.

Contributors

- Nic McKenzie, Henrietta Tripp, Jackie Robinson and Merryn Gott contributed to this section.
- The two stories were gathered during consultation for this report led by Nic McKenzie.

A mother's story

My son was 30 when he died. Ben was a young man with a profound learning (intellectual) and physical disability and long-term frail health. Ben lived in his own home and had a group of long-term carers who knew him really well; they were wonderful and so skilled, and we lived nearby. I always knew Ben would die before me, but I just didn't know when. He nearly died 10 years ago, and I was just not prepared for that. I realised then that I didn't have a plan in place to support Ben at the end of life. Nobody talked to me about palliative care at that time in a way that encouraged me to consider it, and no plan was made.

In the end we had many visits to the hospital. I hated taking Ben to hospital but that's just what we did because we thought that was what we were supposed to do when he was unwell. We'd get there and they'd do blood tests, it was painful for Ben, and they never really knew what was going on. But I knew what was going on was that his body was slowly wearing out. One day, we were there in hospital, and this amazing woman came, a doctor, and she said that she'd never seen anyone with this level of disability this old, and I'd done really well, but it was time to stop being so reactive. And I looked at her, and I thought, 'thank goodness for that'. And she told me that I needed to go home and never come back to the hospital because this wasn't a good place for Ben.

We need people to tell us when to stop fighting it [the illness], and why. Things could have happened earlier than they did. The palliative care team came and sat with me and the rest of the family and Ben's care staff, and we made a plan – it was all about what interventions were acceptable. We decided we didn't want any more needles, no hospital, and no resuscitation, and we talked through that. It was transformational. Once we had the plan in place, we managed really well for over a year and in that time we didn't need to contact the palliative care team. Ben's care team were already highly experienced in supporting his complex health condition, and this, along with the GP and community nursing support, helped us to keep managing well as Ben's health deteriorated.

But eventually as we had expected, things went pear-shaped, and I rang the palliative care team who told me to ring an ambulance. The ambulance staff looked after him while we waited for the palliative care team to come. The ambulance crew offered several interventions. I had to reinforce our decisions. I almost wavered, but I thought, 'no, we'll stick to the plan'. I can't tell you how important that plan was. When they got there the palliative care team kept him comfortable until he died. It wasn't a huge involvement from them, but it was so important.

Our family and the carers (and some of the carers' whānau) were there when he died. My friends all came and we cooked a big meal and ate it together with Ben tucked up in bed. The palliative care team had gone by then. Everyone left except three of us, close family, and we dressed him and wrapped him and the funeral director came and we carried him out to the car and off they went out into the dark night. It was then a matter of just settling into a new world and being very sad.

Overall, palliative care was a positive experience, but it could have helped to be referred earlier. I knew counselling was available through the team, but I didn't use it as I had my own support. I think that is important for families as they need to get their heads around planning for a peaceful, rather than a prolonged end for someone they love. I think there is also a real issue about people who shouldn't be going to hospital – there's not always enough in the community to avoid that and keep people at home. There's no way to get help (like your flu injection, or regular health care) that doesn't involve having to go out to get services. If you want people to die at home and peacefully, there needs to be simple supports in place.

Evidence summary

People with a learning disability have **complex health issues**. These are exacerbated by inequitable access to education and employment, and an increased likelihood of having a low income, living in an area of deprivation, and experiencing loneliness. Diagnostic overshadowing can result in the **late diagnosis of health conditions**, including life-limiting conditions, because problems are incorrectly attributed to the person's disability.

I certainly see that issue of overshadowing a lot..[with] clients...they perceive the problem being the [learning disability]. Anxiety disorders in particular I think are overlooked... it's just put down to the fact they have an intellectual disability whereas in fact they are actually depressed (Service provider).²¹

Most healthcare professionals lack confidence and knowledge in caring for people with learning disabilities, resulting in **negative experiences of healthcare**.

I think services are afraid of the unknown and so as soon as they see the [learning disability] they pass it on and get rid of it quickly because they don't have the expertise or they don't have the confidence (Service provider).²²

Palliative care requires good communication about sensitive topics. However, **health professionals receive limited training** in how to best communicate with a person with a learning disability.

Some staff members don't know how to interact or listen to or communicate with the person, which is a poor reflection [on] nurses' training (Service provider).²²

Poor communication can translate into **negative outcomes** for people with a learning disability.

[We experienced] a doctor not explaining a medical procedure in a way that the [person] could understand, resulting in [the person] saying 'no' to an important medical procedure (Lived experience expert).²³

People with learning disabilities are **dying young**, in ways that are **perceived to be unexpected** (due to late diagnosis), and this **largely occurs in hospital**. Negative experiences of being in hospital are not uncommon and reflect healthcare professionals lack of experience and at times reluctance in caring for people with learning disabilities, as explained by a family member:

He reckoned [my sister-in-law] wasn't his patient... One of them reckoned she was a surgical patient and the other one reckoned she was a medical patient... they stood there and argued about that; nobody wanted to look after her... I said 'no – she is not going to be zonged to the eyeballs just to keep her quiet' (Lived experience expert).²⁴

People with learning disabilities value being supported to express their end of life care wishes through **Advance Care Planning**. Making an Advance Care Plan, and ensuring that people around them are aware of their preferences, can lessen their anxiety associated with end of life care. As a person with a learning disability shared:

[If we make plans] then we don't have to worry about things (Lived experience expert).²⁴

I thought a lot about it. It's a good idea [doing an Advance Care Plan], then the person knows what you want and can listen to that (Lived experience expert).²⁴

Conversations around planning for care at the end of life can be a positive experience. They help support autonomy, choice and agency for people with a learning disability, as one family member discussed:

[This is] an amazing thing for Andrew, opening his mind as far as he currently wants it at present [by supporting him to develop an Advance Care plan]. The groundwork is laid for continuing along the path of life....and it's good for Andrew, because it's clarified a lot of things in life, I think. Everything popped into a place, so it's a very worthwhileum, I was doubtful, I thought it would be agonising for him (Lived experience expert).²⁴

Clarifying and documenting the care preferences of a person with a learning disability can also support health professionals. Being clear about their wishes, and having these documented, can build knowledge and confidence in providing appropriate palliative and end of life care. As a family member shared:

The GP was really pleased...what we had written was exactly what she said, so they were more than happy, and it was all signed and done (Lived experience expert).²⁵

Support workers often have a close and long-standing relationship with people with learning disabilities. They are therefore in a unique position to support end of life care conversations and facilitate the planning and delivery of care if they are well informed about the person's wishes. As one service provider shares, this brings them a level of confidence in supporting someone with palliative care needs.

We have some people in palliative care, and now we realise what to do now. And we have the questions now, that we could have done 5 or 10 years before. If [Advance Care Planning] is in place that would be really good. If we have this in place, we know what to do (Service provider).²⁴

A disability service provider's story

My first experience of being a residential disability service manager and supporting someone who was seriously unwell was so hard. They didn't have any family, and I didn't really know what I was doing or who to ask. There are so many things to navigate. Health services think that we have teams of nurses and provide medical care, but we don't. They don't understand what disability services are about. Somehow though we are expected to become the specialist about health.

People with learning disabilities get a poor deal with healthcare a lot of the time. There's a lot of bias. If you have skills and money and can advocate for yourself you get really different service from the health system, good service. A lot of the people we support don't experience that. In hospital, we've had a lot of people discharged too early, and then they get sicker and have to go back. If people are re-admitted, we need to then have managers there to advocate and get the right information, to consistently and firmly ask questions, and not give up until it's sorted. Medication is another thing; a lot of people are over-medicated. People get put on medications that should only be for 2 weeks, and they're still on them 6 months later, or 20 years later. It's still a huge issue.

The healthcare problems are still there at the end of people's lives. A while ago we were supporting a lovely person who had been in and out of hospital in the few months leading up to her death – she had high blood pressure, high cholesterol, was overweight, had a family history...but the person didn't get any advice about what to do to look after their health, any preventative things to decrease the risks. Looking back there's a picture to see, and we hadn't asked 'what is this telling us?', but nor had any health professional. Sometimes people are really sick, too sick to leave home, but some GPs won't do home visits. What do we do then? Does the person have to change GP when they get to that point just so they can see a doctor? We had another situation where a doctor suggested that a person's family needed to get do-not-resuscitate order in place. The family then found out it wasn't legal for them, or anyone other than the person themselves, to make that decision. People with learning disabilities have the same rights as everyone else. I don't think anyone asked the person what they wanted.

We've found it really good to work with the palliative care teams. They really want to understand the people we support and find out what learning disability is about, even though they do find it really different. They don't get any education about that – I don't think many health professionals do. They have provided training for all of our staff when we had someone dying. They make the training about who the person is and what they want and what would work for them. It's so important that the person is involved in all of the discussions and decisions. Everyone was really reassured by that. When she was dying, they came in and helped and got to know everyone really well.

People with learning disabilities usually prefer to be in familiar places, with familiar people, where they can understand what's happening and where they are also understood. We really want to do everything we can to help them stay at home until they die, if that's what they want. It's usually better than being in hospital, where people can be scared or anxious. But we just do what we need to do to support people. We make it work.

Palliative Care for Children and Young People



Context

- Around 350 children die of a serious illness in NZ each year. Ten times this number are estimated to have palliative care needs. Due to medical advances the number of children who would benefit from palliative care is predicted to increase.
- Most referrals to a specialist paediatric palliative care service have non-cancer diagnoses.
- Most children with palliative care needs are cared for by their primary paediatric team.
- Starship Palliative Care is the only Te Whatu Ora funded specialist service for children. Small numbers of clinicians with training and expertise are situated in Hamilton and Christchurch. A newly established, charity funded specialist paediatric palliative care team is based in Wellington.

Contributors

- Gemma Aburn, Jackie Robinson and Merryn Gott contributed to this section.
- The service provider story was gathered during consultation for this report led by Gemma Aburn.
- The grandmother's story was provided by Tess Moeke-Maxwell.

A grandmother's story

After a routine hospital antenatal scan, my daughter Racheal was told that her baby had a small hole in their heart. She was referred to a large urban hospital because they had better scanning equipment. She wasn't told that her baby could have a life-limiting illness and she wasn't advised to take her partner to the next meeting either. She just thought this would be another routine scan. My daughter was told the devastating news that her baby had restrictive cardiomyopathy and would die before, during, or shortly after birth. She was in shock and on her own. She then had to drive three hours to get home to her partner.

Before Te Minaora's birth, my daughter Racheal and her partner Phil along with their whānau met with the cardiology team. The doctor at the hospital was really supportive and tried to talk about palliative care but I think Racheal was still holding onto some hope that Te Minaora would survive. But I needed to know more so that when Racheal was ready, we could get the help we needed. I guess we all have different need for information at different times. I needed to hope for the best and plan for the worst. In the end we were not contacted by anyone from palliative care; apart from Racheal's midwife who supported her during the birth we got no formal support to help prepare our whānau for Te Minaora's anticipated death. There was no advance care planning in place. We were not told how we could manage Te Minaora's pain or distress if she was dying.

They were informed that they would be contacted by a paediatric palliative care nurse who would be able to visit them at home and provide guidance and support. They never received any contact or support with the preparation for Te Minaora's arrival. No advance care planning or support with planning for pain or distress that may arise for Te Minaora as she was dying.

Hospital visiting was very restricted at the time due to COVID-19 related hospital visiting restrictions. Racheal feared being without Phil and me, so she chose to give birth at home. Te Minaora was born on 5 April 2020. Everything went very well for 24 hours until a small hiccup developed, and she became a dusky colour and stopped drinking. Racheal and Phil took Te Minaora to the hospital. The staff were very kind and confirmed their baby was dying. Racheal and Phil were in shock and away from any other whānau supports. They could not fully absorb the information they were given about administering morphine to their dying baby.

Once home, Te Minaora had a significant event causing her severe physical pain – her back arched like a rainbow; her parents were distressed at what they witnessed. They did not know if they should administer more morphine and didn't have anyone to call for support.

In hindsight, it would have been helpful if staff had used tele-health methods to include other family members during their meeting about how to give morphine and support Te Minaora when she was dying. It was all so hard to take in on their own. It would also have been really helpful to be given written instructions on how to manage the frequency of administering morphine for pain management.

Te Minaora died peacefully in her mother's arms early evening 6 April without any paediatric palliative care support at home. The parents were grateful that a family friend with a palliative care background visited them to offer her support.

Evidence summary

Whānau and families want their child referred to by name, involved in all discussions and **recognised as experts in their care**. They highlight that it is important for health professionals to establish their child's likes and dislikes. This is particularly the case for children with neurodisability who make up the biggest portion of children with palliative care needs.

Listening is the most important way you can connect. AJ's voice needs to be heard – in day-to-day care, in decision making always (Lived experience expert).²⁶

Effective communication involves learning how to best **communicate with children**.

Some of [the nurses] knew sign language too. I do think that [they] made a special effort, and I do feel grateful [breaks down] to them for that, (Lived experience expert).²⁷

Some families reported that **discrimination due to disability** is common and that they want disability to be integrated seamlessly into health consultations:

I don't know whether families without disabilities feel on an island as well, maybe we all do, but.... there's times where you feel really left out (Lived experience expert).²⁸

Whānau and families stress the importance of support from palliative care teams, but report that it can be **hard to accept a palliative care referral** as it involves acknowledging how unwell their child is.

I was terrified when they mentioned palliative care – I thought my son was going to die imminently, I knew he was really sick but I hadn't considered he might die soon. I realised that you weren't scary and were able to help us navigate a difficult situation – give us a voice, and ensure our boy was able to get on with the living despite being so sick (Lived experience expert).²⁹

Parents report a **gap in access to accurate and consistent information** about their child's diagnosis and treatment. This includes a lack of developmentally appropriate information for other children about their sibling's condition. Finding inconsistent information online can be overwhelming and add to their distress.

There's no chapter about the final stage of illness. And that's what's missing.... There is a gap and I think that relates to our society not being very open about death (Lived experience expert).³⁰

Health professionals feel that the **low priority afforded to paediatric palliative care** in NZ in policy, service delivery, and funding is leading to increasing inequities in access to paediatric palliative care. They feel this is particularly true for whānau living in rural communities, and for children who have a non-cancer diagnosis.

Paediatric Palliative Care in Aotearoa once led the way internationally, but a lack of funding and recognition of the value of palliative care for children has meant we have fallen behind and children no longer have ready access to palliative care. Inequities are increasing and whānau Māori, children with a non-cancer condition or those that are living outside of Auckland don't have the same opportunity to quality care. Even in Auckland it is now hard to get timely access to a Paediatric Palliative Care specialist (Service provider).³¹

Primary pediatric teams identify a **need for education** in paediatric palliative care.

I'd like to feel more confident about how to talk to families... just knowing how to phrase things maybe a little bit better and just to how you go about making a better plan for

medications that we can get hold of to give to families for their child in that circumstancemaybe what availability there is for siblings [and finding a] support network for them as well (Service provider).³⁰

They particularly want to **learn more about palliative care for tamariki Māori** and their whānau and identify a gap in current provision that is rooted in a Te Ao Māori approach:

I certainly look after quite a few Māori families with children with disability and chronic illness of various types and various severity but ...yeah its still done in a very western style (Service provider).³⁰

Health professionals providing generalist palliative care report that **palliative care education makes a difference**, as does being connected to other professionals involved in providing palliative care:

It's changed my overall confidence in dealing with these things, not that I'm feeling over confident, but there are things I know and there are things I don't know, the things I don't know I now have a network of people I can reach out to who are always there, but now that just seems that little bit more familiar (Service provider).³⁰

A nurse specialists' story

In the health system we constantly talk about how we can reduce inequity for children and whānau. This is particularly important for children living in deprivation, tamariki Māori and whānau, Pacific children and families and those living in rural isolation. Despite this, we see inequity in our work every day. As I reflect upon the inequity that exists within paediatric palliative care, all whānau I think of either live remotely, or have had challenges engaging and accessing the increasingly complex health services in Aotearoa. Of note, all of these whānau identify as Māori or Pacific. A recent young person I worked with comes to mind: Tama.

Tama was a 16 year-old Māori boy who lived in a rural and isolated part of Aotearoa. He lived 1.5hrs away from his local hospital and paediatric palliative care team. I first met Tama at Starship, while he was receiving chemotherapy and radiotherapy for Ewing Sarcoma. Tama was a delightful young man, who had experienced a challenging childhood. He was well known to mental health services due to self-harm, previous suicide attempts and autistic spectrum disorder. Tama had developmental delay and was struggling to keep up at school prior to his diagnosis. Tama lived with his mother and was an only child. Tama's mother battled methamphetamine addiction for many years and had recently completed a rehabilitation programme. Tama had no other family support. Tama was well known to Oranga Tamariki and had previously had a youth worker allocated to support him.

Being so far away, I had never visited their home. However, a recent meeting held via zoom with his local paediatric team and the adult hospice nurse highlighted the significant deprivation the family lived in. The house was freezing cold and they had no food. Mum did not have a driver's license or access to a car and there was no reception to be able to use the phone Tama had received from a charity since diagnosis. The team had needed to leave the home on several occasions out of fear for their own safety due to Mum's volatile behaviour.

The local team presented a story of Tama having significant and rapidly escalating back pain. It was unclear what doses of medications Tama was taking. Tama was having to independently manage his medications. Tama also was unable to pass urine and found it difficult walking around his house. Tama had developed a spinal cord compression. Despite usual treatment for this being emergency radiotherapy and steroids, this required Tama to travel at least one and a half hours to an adult radiation centre. A young person living in central Auckland would be in Starship and receiving radiation within 24 hours – with the outcome of potentially regaining bladder function and mobility. This was never possible for Tama and the travel alone meant he decided he did not want to pursue radiation. Tama received no whānau support to make his decision. Adult hospice providers seeing him at this time were not aware of his developmental needs or how to best support him in a developmentally appropriate way.

We managed to get the local paediatric team and hospice nurse to go in and support Tama together. They helped arrange social supports to ensure Tama was able to receive the most helpful treatments to optimise his comfort and quality of life. However, despite best attempts to support Tama, I feel sad that he still missed out on quality palliative care. Tama was admitted to an adult hospice for end of life care. He received care that was adult-centric and didn't acknowledge his unique needs as a young person with developmental needs.



Section 2:

MĀORI AND PACIFIC

EXPERIENCE OF PALLIATIVE CARE

Māori experiences of Palliative Care



Analysis framework and contributors

The following section provides a summary of the Aotearoa New Zealand published research pertaining to the experiences of palliative care from a Māori perspective. Te Tiriti o Waitangi was adopted as a framework to guide the analysis as it centres the notion of equity. The intention of the Crown set out in He Kupu Whakataki, the preamble to Te Tiriti o Waitangi, was to protect both Māori and non-Māori from harm.

The full literature review including references and links to relevant websites is available as a separate report which is available on request from the research team. Whānau digital stories which highlight Māori experiences of palliative and end-of-life care can be viewed on [Te Ipu Aronui website](#).

This review was led by Kathleen Mason (Rongowhakaata, Ngāti Porou) and supported by Stella Black (Ngāi Tūhoe, Whakatōhea, Ngāti Whakaue), Tess Moeke-Maxwell (Ngāi Tai ki Tamaki, Ngāti Porou), Whetu Meihana (Rongowhakaata, Ngāti Porou, Ngāti Apa ki te Rā Tō, Ngāti Rārua, Ngāti Kuia) and Melissa Carey (Ngāti Raukawa, Ngāti Huri).

Evidence summary

Ko te Tuatahi - Kāwanatanga: 'good governance' that is 'fair, just and ethical'

For health equity to be realised distribution of resources needs to be fair and just rather than equal. Different resources may be needed to achieve the same outcomes for different groups. Understanding Māori realities and world views is essential.

Māori experience racism and discrimination. Racism obstructs whānau [rangatiratanga](#), as in this example of a whānau participant reflecting on what she was told by a health professional regarding the administration of morphine at home:

She said, "So which one of you are going to learn to give the Morphine", in the other breath she says, "no-one will steal it will they", and then to turn around and say "I'll be back tomorrow to give it", then she turned around and said, "only her can give it" (Lived experience expert).³²

Aspirations for Māori-led and Māori-run palliative care services are evident. Research with tangata whenua in the Bay of Plenty has informed the development of a kaupapa Māori model of practice for palliative care.³⁵ A whānau participant from one study commented:

One of the things I think would make it better is that we had our own people to be that provider, to be that other place to go to, rather than just have this one palliative provider and nowhere else you can go to but there, to have some of our own people in that area, so that we are comfortable (Lived experience expert).³²

Reliable and consistent government-backed resourcing is needed for services to be sustainable. A previous Māori-led palliative care service has ceased operating demonstrating how easily options for Māori can be removed.

Traditional palliative care services are not always perceived to be culturally safe by Māori or being able to meet their needs. Māori report that services often overly focus on physical care, do not listen to the patient or their whānau, and have limited regard for care related to the "social, emotional and spiritual" domain.³³

Māori are more likely than non-Māori to experience **economic deprivation**. For those with fewer financial resources, the economic burden of end of life caring can be long-term and serious. As one study participant observed:

Sometimes our families they don't even have the means. They're already bogged down in bills (Lived experience expert).³⁴

Ko te Tuarua – Tino Rangatiratanga: 'the right for Māori to make decisions for Māori'

Māori need to remain in control of and decide what is the best palliative care for Māori. The **top end of life priority** for Māori of advanced age is to not 'be a burden to family/whānau'. Care of whānau is perceived to be an important benefit of hospice care within this context:

And um that's what I'd like. I'd like, to see is that the whānau can just go in and be there and help if they need you. Maybe your whānau can see the ones that are helping in there are doing what your own child would do, you know. They might be happy with that but so long as that their family can come in and just have a look whenever so that they're not tied down all day to look after you (Lived experience expert).³⁵

End of life care priorities for Māori also include:

- maintaining independence
- honouring cultural obligations in the community
- being cared for by whānau
- preferences for symptom management met
- being connected to whānau and whenua
- dying at home

Caregiving at home can be hard, particularly when carers are having to navigate the different services involved in end of life care and advocate for their whānau member. They can feel unprepared and afraid when they do not know what to expect at the end of life.

If you have x cancer, what and where is it going to hurt, am I going to get headaches, am I going to be able to stand up, you know. At the beginning this is what it will be like, in the middle and at the end. Cos you don't really know where you are at this time... It's the unknown stuff that drives you nuts (Lived experience expert).³²

While home represents **safety and autonomy**, inpatient care may be required. Māori staff act as **Ngaio Whakaruruhau**, or professional and expert protectors, to create a safe space in healthcare settings for Māori with life-limiting illness and their whānau. For example, whānau describe how, after their father's death, a cleaner entered the room to **whakanoa** by removing tapu:

Once Dad passed, as we left, then this wāhine comes in . . . she was a cleaner I think she was? But she came in. She was, mm, in her. . . early 60s. . . and she looked at Uncle A and Uncle A looked at her, and he goes "I've completed it, I've already done it". And she goes "Ok". Her other role was to come in to clear, (Lived experience expert).³⁶

However, work to support Tino Rangatiratanga often has to be **justified, or hidden**. For example, a Māori nurse reflected:

The most challenging, would be the justification of . . . [using] a custom. Why do I have to justify what I'm doing as Māori? . . . To either the health professional [or] the services? (Service provider).³⁶

Rangatiritanga is important in inpatient care and whānau often want to be involved in providing personal, spiritual and cultural care. One whānau participant shared how they supported the mana of a dying whānau member by protecting his privacy:

Like when you're working with the nurses, and I'm learning too, all the time, when there's an opportunity to learn to do something better ... Family feel helpless, 'cause they don't know how to care, they've never done it before. These are little ways that they can feel a part of helping (Lived experience expert).³⁷

Ko te tauru - Ōritetanga: Māori have the right to equitable outcomes as well as equitable access to publicly funded health and social services

Previous negative experiences of health services can create barriers to accessing palliative care at the individual/whānau level. Additional barriers can be created by ineffective communication by health professionals through the development of misconceptions about:

- options for whānau caring for a family member at home.
- palliative care being associated with imminent death or hastening death.
- hospice thought of as a place for older people or people with cancer.

- moving from curative treatment to palliative care.

Having choices and, more specifically knowing what those choices are, is critical to inform decision making for Māori whānau; not knowing what healthcare services are available negatively impacts the rangatiratanga of Māori. Late entry into palliative care services can be a source of frustration for whānau and health professionals alike and a barrier to

whakawhānaungatanga:

The whānau needs to know, to have a clear explanation of what hospice services...not provides but wraps the family in ... They need to know, to ensure that the whānau fully understand (Service provider).³⁸

Māori are more likely than non-Māori to live in **rural and remote areas**. The challenges in accessing palliative care and end of life services in rural areas include:

- distance between home and inpatient services. Separation from whānau can affect the mental and emotional wellbeing of the whole whānau.
- access to medication and equipment.
- travel to appointments.
- lack of services afterhours.

Access to appropriate palliative care support can help to sustain whānau caring for whānau at the end of life. Benefits reported by Māori include continuity of care, having an afterhours contact, access to care equipment at home, spiritual support, and counselling and bereavement care for whānau.

Ko te tuawhā - Wairuatanga: commitment to tikanga values and practices and spiritual wellbeing

Māori cultural care values help to sustain whānau when a whānau member is dying, including: whānaungatanga, whakapapa, mana, mauri, aroha, manaakitanga, rangatiratanga, kaitiakitanga, kotahitanga, wairuatanga, tapu and noa. The importance of observing tikanga related to tapu and noa when caring for kaumātua, particularly for older men was evident when one whānau participant said:

They choose someone to handle them especially when it comes to their naked body, that's something that is very tapu to them, (Lived experience expert).³²

Māori cultural practices by whānau can help soothe the dying and the whānau. Practices including karakia, waiata, providing special kai, using water, tikanga, speaking te reo, and rongoā rākau help to prepare a loved one to pass through the ārai.

*Some nurses will say 'oh that [rongoā rākau] might interfere with their aspirin' or 'that might interfere with whatever', but at end of life I think 'what the f***, just give it to them.' Yeah, they [Doctor] goes 'Oh hold off on that in case it interferes with your medication.' [I think] 'Just wait until they leave, I guess (Lived experience expert).³⁹*

Cultural ignorance from healthcare professionals can result in negative experiences:

Nurses just waltz in unannounced; the doctors don't care what they interrupted. We were having karakia and they walked in and stood at the door to wait – they weren't part of our karakia and invited themselves in (Lived experience expert).⁴⁰

Tikanga is used to manage the **spiritual wellbeing of the living** after a loved one has died. The architecture of Western health services creates barriers to the care of **wairua**, including insufficient space and a lack of privacy while transporting **tūpāpaku** within a facility. Efforts made by hospital staff are appreciated by whānau:

In that single room, we pushed her round there, and then she died the next morning. She wanted to be with the other people and that was, that night was when I slept with her, because I didn't want to sleep in the ward with the other people, it's disruptive to them and their visitors. That's all I wanted – the single room so I could sleep there whenever we want, so we can make a noise if we wanted to (Lived experience expert).⁴¹

Māori kaimahi act as a conduit between te ao Māori and the Western world to provide **holistic whānau-centred end of life care**. Whānau appreciate seeing Māori kaimahi, as this participant stated:

It was like just going there and seeing that friendly face and I guess for me as well, I identify quite closely with her cos I see a Māori woman when I go and see her, and I guess that familiarity more than anything, is good to have (Lived experience expert).⁴

Pacific people's experiences of Palliative Care



Context

- The Pacific community in New Zealand accounts for 8.1% of the overall population and comprises eight main Pacific nations: Samoan, Tongan, Cook Island, Niuean, Fijian, Tokelauan, Tuvaluan and Kiribati group.
- None of the Pacific home nations have hospice care centres, so all care for those who are dying takes place either in the hospital or at home, where all caring and caregiving tasks are provided by the family.

Analysis framework and contributors

The following section provides a summary of the Aotearoa New Zealand published research pertaining to the experiences of palliative care for Pacific people. The Vā model was adopted as a framework to guide the analysis. The Vā is not an empty space, nor does it separate, but it is a space that relates. This space provides context and gives meanings to things, so the relational space changes as the relationship or the context changes. Embedded in the concept of the Vā are the values of love, respect, reciprocity, and service. Each of these values governed and informed the way the analysis was conducted, ensuring a contextually meaningful approach so the palliative care experiences of Pacific people in Aotearoa New Zealand are presented credibly and respectfully.

Evidence summary

The full literature review, including references and links to relevant websites, is available on request from the research team as a separate report. Digital stories which highlight Pacific people's experiences of palliative and end of life care can be viewed on [Digital Stories Asia Pacific](#). This review was led by Elizabeth Fanueli, a researcher of Samoan descent who was raised in Auckland, New Zealand. Support was provided for the review by senior researcher Dr Fuafiva Fa'alau who is also of Samoan descent.

Perceptions and experiences of palliative care are mediated by culture. As a lived experience expert describes:

For me the only word closest to palliative in Samoan is 'tausi'. For me, tausi means... caring for someone you love or hold dearest, with 100%. It's about caring with love, faithfulness, and serving well (Lived experience expert).⁴

There is no word for 'palliative' in Pacific languages and the role of palliative care **has not been adequately communicated** to Pacific patients and their families. Pacific people who need to access palliative care services often do not understand the purpose and philosophy of the service. Pacific people also report that services do not align well with Pacific ways of knowing and being.

Negative perceptions of hospice are common. They are often likened to rest homes which 'are a concept that just doesn't seem to gel well with the Pacific Island psyche' (Lived experience expert).⁴⁴

Hospices are also seen by lived experience experts as a 'step to the mortuary':⁴⁵ the place you send family members to die. However, **positive experiences of hospice** have been reported by Pacific people who access them. As one lived experience expert shared:

How they cared for us was incredible. I don't think we would have been able to sort of cope with what was happening, cause they allowed us to breathe and come away which was important for us (Lived experience expert).⁴

There is an ongoing need for **Pacific interpreters and Pacific liaisons** across all healthcare services, including hospice and palliative care. Furthermore, all health professionals need to be **culturally responsive** in their communication and interaction with Pacific patients and families.

Older Pacific people, especially those born and raised in the Pacific Islands, perceive questioning a doctor or clinician as **disrespectful or distrustful**. They may therefore agree with everything said by health professionals, but not completely understand the issues being discussed.

The Vā (gendered caregiving activities pertinent to Pacific peoples)

In general, only **same gender nurses** should provide personal care for Pacific people unless staff have checked with the family. A Samoan daughter adds:

They were changing my mum but there was a Palagi (European) man there and the Island lady was doing the changing. I was really angry (Lived experience expert).⁴⁶

This can result in people choosing end of life care in hospital to avoid, for example, sisters providing care for brothers at home. There are occasions when opposite gender care can occur, but these decisions must be based on **family discussions** to ensure the dignity and respect of a family member is still upheld.

A core value of being Pacific is caring for your parents and relatives, and the extended

family become a support system to assist the main carer. In understanding the Vā and the care, protection, and love that parents or grandparents provide for their children and grandchildren, it is only natural and responsive for (grand) children to want to give that love, care, and protection back to their family members. Many of the lead care decisions and responsibilities are likely to fall on **Pacific women** in the family, either wives or daughters. As one daughter states:

I'm the only girl, I've got three older brothers, they've all got families and other commitments. I, on the other hand, (laughter) have not got any attachments at the moment, but of course being of Cook Island descent, it's family first (Lived experience expert).⁴

The **sacrifices** made by the lead carer are an integral part of caregiving in the Pacific context.

I gave up my fulltime job to become my Mum's fulltime caregiver. But, more than that, I had to miss school events with my kids. I couldn't be there for the preparations of my daughters' weddings. But none of that matters in the long run because Mum is my main priority (Lived experience expert).⁴

Pacific caregivers note that their need to make sacrifices can relate to the **high economic costs of end of life caring**.⁴⁷ As one family carer discloses:

Sometimes the children are fed and we adults just have the leftover, so we could make ends meet. But we always think of it as temporary... Things will be back to whatever we usually do (Lived experience expert).⁴⁷

Importance of Spiritual Care

Me, my children, my community and my church created a network of prayer. The force kept us strong (Lived experience expert).⁴⁹

Spiritual wellbeing is essential to Pacific people and **prayer and singing hymns** plays a vital role in caregiving practices. Appropriate spiritual support in all care settings at the end of life is crucial. However, Pacific families report **dissatisfaction** with the spiritual support provided by hospice. Specifically, they are often unaware of available support, or receive support which does not meet their spiritual needs.

The spiritual need **to return home to the place of birth** is common, particularly for older Pacific people, and often family members will take their loved one back home to fulfil a dying wish. Ultimately coming home, plays a critical role in maintaining their sense of independence and meaningful existence once curative treatment is stopped and death has been accepted. Therefore, despite the financial implications, Pacific families will often do what they can to ensure the body of their family member is taken back home to their birthplace for burial.

Culturally responsive communication and information delivery

Generally, connecting and communicating with **healthcare professionals from the same culture** provides a better experience for Pacific people.

It was being explained to her by a Pasifika in the field, so they can talk the mother tongue. And then her demeanour just changed, so much, it was like, thank you so much, thank you so much, I understand (Lived experience expert).⁵⁰

Whilst many Pacific families prefer to receive care from Pacific health professionals, this is often not possible. What is important is that **health professionals are culturally aware and responsive**. As one lived experience expert shared:

If professionals are not Islanders, [to] be culturally aware there is stuff you can do...have someone who is friendly. I would want someone who is empathetic (Lived experience expert).⁴⁶

Building rapport and trust, and understanding that end of life decision making is a collective family affair, can facilitate better communication between healthcare providers and Pacific patients and families. Recognising **the role of the family caregiver as an advocate** for their family member is also important. Many Pacific family carers report that if they did not fight and push to be heard, their loved ones would not receive the tests, the resources or the support they deserved. As one caregiver communicates:

How much longer could it have gone, if, I didn't push and say, oi it's not good enough... I want answers... something is wrong (Lived experience expert).⁵⁰

Pacific family caregivers report **frustration and grief** when communication with health professionals' breaks down. This may result in family members not understanding that death may be imminent. As one daughter shares:

I think that's what breaks our heart - if we had that. No one in the last month said, "your Dad's not looking too good", we would have shifted (Lived experience expert).⁴⁶

Culturally responsive communication between health professionals and family carers is also needed to ensure that **pain and suffering** is addressed sooner rather than later. For example, culturally appropriate information is also needed to support Pacific families to better understand the role of **morphine at the end of life**, which some link to euthanasia. As one family member shared: *[hospice] gave my father a morphine, which caused him to die (Lived experience expert).⁵¹*

Pain medication may also not be prescribed when a person does not 'show' they are in pain; as a caregiver asked, *how do we know she needs it [pain relief]? she's like, she needs it... because she can't say it anymore, she's sleeping but she's in pain.*⁴⁶ Better understanding is needed of Pacific people's preferences around pain relief at the end of life.

Pacific family carers also feel they need **training** to ensure they are providing adequate care at home, and are doing no harm, especially around administering medication. They **can also struggle to access appropriate information and resources** to support their caregiving work. A lived experience expert explains:

Getting the information... little things like that... getting their equipment and who did they talk to about getting that equipment, who does all the assessments for them to get that equipment (Lived experience expert).⁴²

Information may also not be translated into the language they speak. People use their own **Pacific networks** to find out information and share it with their family. This is all part of nurturing the Vā (space) and relationships within Pacific communities. Pacific people willingly help out and share information and experiences with each other.

Place of care

Being surrounded by family, extended family and the wider community is a key reason Pacific people express a **preference to die at home**. One lived experience expert comments:

I prefer to die comfortably at home and have heard many negative things about hospices (Lived experience expert).⁵¹

Pacific people are more likely to die at home than New Zealand European people. However it is unclear whether this is due to cultural/personal preference, or poor healthcare access. It may also relate to the fact that Pacific people with palliative care needs report significantly

more burden during a hospital admission than other ethnic groups.

The role of general practitioners in the palliative care journey

Pacific families report good experiences when their GP explained the role of hospice and continued to be involved in their care, even when their family member was referred to hospice.

Good continuity of care was related to the longevity of the relationship many Pacific patients and their families had with their GP. One Samoan daughter discloses:

It really helped having our GP there. Dad was always praising the GP because when we were with the other GP when we were going through this, it was a guessing game... but with the new GP it was real good (Lived experience expert).⁴⁶

There may be a role for GPs in supporting Advance Care Planning (ACP). Additionally, ACP information needs to be available in Pacific languages. However, this is a complex issue as Pacific people have also raised concerns that APC is not aligned with their culture and spirituality. A Pacific service provider explains how engaging in ACP shows that *we don't have faith, [because] while they are still alive, there's still room there for a miracle.*⁴⁵

Section 3:

Where to from here?

This section provides two resources to guide people who want to begin to address inequities in palliative care. The first is a conceptual framework developed from the Te Whakahekenga (Dying as a Health and Social Justice Issue) findings which can be used as a practice guide when working with underserved communities. Finally, we conclude with some suggestions to support individuals and organisations who want to contribute to much needed equity efforts in palliative care.

He Tapu Te Tangata/The Sacred Person

He Tapu Te Tangata/The Sacred Person is a conceptual model which acknowledges the need for health care professionals to respect the sanctity or wholeness of a person. It can be used as a living model and practice guide when working with underserved communities.

It is a living model that can be used as a practice guide when working with underserved communities. Healthcare professional should be aware of the following te ao Māori concepts when connecting with individuals/whānau: [Whakamana](#) to empower and uphold [mana](#). [Whakaiti](#) avoid humiliating and diminishing. [Whakahīhī](#) is a concept that looks beyond seeing conceit, pride or arrogance as intelligence (Keri Kaa, 2014). [Whakamā](#) is felt as [mamae](#) or [pāmamae](#) that impacts the mana of a person. [Whakararu](#) recognises the problems, barriers or blockages leading to whakamā

The te ao Māori concepts used in this model are interconnected and influenced by other [tikanga](#) imperatives. Each [niho taniwha](#) (triangle pattern) speaks to a different components of He Tapu Te Tangata. Examples of whakamana, whakaiti, whakahīhī and whakamā dialogue between individuals/whānau (in blue) and their healthcare professionals (in green) are provided. This dialogue is not exhaustive nor is it prescriptive, instead it provides an example of how He Tapu Te Tangata can be integrated into practice. While the pervasiveness of the whakararu or problems (in black) encourage healthcare professionals to actively interrogate their assumptions about an individual that may present differently to themselves.

Differences may include but are not limited to how a person looks, how they speak or how they have lived their lives. It may also include things not so visible, such as values and beliefs about health and wellbeing, death and dying as well as past traumatic life experiences that may be triggered during a health consultation. In response the healthcare professional will adjust their approach, perceptions, behaviour, and reactions to each individual/whānau taking into account the sacredness of each person reflecting the very concepts outlined in He Tapu Te Tangata.

Our vision is for all health care professionals to consider embracing this model into their practice and contribute to improving inequities for all New Zealanders. He Tapu Te Tangata builds on the Te Whare Tapa Whā developed by Sir Mason Durie as well as the Hua Oranga measurement tool and training by Te Rau Ora. He Tapu Te Tangata asks healthcare professionals to consider the sacredness of each person to provide appropriate care for people currently underserved by health and palliative care services.

He Tapu Te Tangata/The Sacred Person



He Tapu Te Tangata/The Sacred Person

I am mamae (in pain). I feel shame, judged and persecuted for who I am. I am different to you.
I can see we are different.

Know that I might have or continue to have trauma in my life. Feel my pain.
I will not make assumptions. Lead me to where you want to go, and we will work it

I have Mana
I see your strengths

Ask me what I want?
I will ask you who/what/why/when and how you want to be supported.



I am humble and quiet, but you may think I am dumb, withdrawn or not listening to you.
I'm ok with your silence.

I don't feel I can speak up even if what you are telling me is not right or it's not what I want.
I'll keep coming back to you even though it might feel uncomfortable for me.

I am knowledgeable, confident and assertive, but you see it as aggressive and angry.
I can see you are angry, scared, uncertain and unsafe.

- Colonisation
- Deprivation
- Verbal communication
- Culturally sensitive
- Non-verbal communication
- Avoid stigmatisation
- Language
- Avoid labelling
- Avoid assumptions
- Powerlessness Avoid
- Avoid judgement
- Trauma Informed
- Helplessness

Barrier to accessing palliative care: Experiences of trauma feature strongly across all groups under served by traditional palliative care services. These groups also often experience barriers to accessing mainstream healthcare. Trauma may include, but not limit to abuse, violence, colonisation, addiction, refugee status, discrimination, persecution, disadvantage, poverty, lack of access, family conflict, lack of rights and limited agency.

Developing meaningful partnerships

The following guidance draws on our combined decades of experience working as service providers and researchers in Aotearoa New Zealand to reduce inequities in access to palliative care. We have also called upon the extensive skills and experience of our Canadian colleagues who have worked extensively with hard-to-reach communities. We wish to share our collective learnings to help palliative care services, clinicians and researchers who are wanting to undertake similar work. We are not being prescriptive: all efforts must start with, and be led by, the communities we work with. In Aotearoa New Zealand they must also start with Te Tiriti o Waitangi and support mana motuhaka.

Aotearoa NZ: Stella Black, Merryn Gott, Tess Moeke-Maxwell, Jackie Robinson, Lisa Williams

Canada: Carren Dujela, Hollie Prince, Kelli Stajduhar

Principles of working

Start with yourself

Recognise that it is your job to educate yourself and be reflexive as you learn about yourself. This needs to occur before engaging in equity work. Reflect on your privileges and the power you bring into the relationship. Interrogate why you want to do this work. Keep in mind that whatever community you enter into, it is your responsibility to be informed and not the community's responsibility to educate you.

Commit to building strong, authentic relationships

Be aware that individuals, whānau/family, hapu/iwi and other communities are capable. They will understand solutions to any of the challenges they experience. There is also likely to be organisations and people in roles supporting them with whom they have trusted relationships. Your role is to learn, build relationships, provide support, and ask where you can best contribute and be an intentional ally. Do not take over. Refrain from telling, instead be open to listening and learning.

Understand the inequities built into palliative care (and all health services)

Understand the history of palliative care and who it serves and who it doesn't serve. Recognise that current models of palliative care would look different if they were developed by and for the communities you are now looking to reach. Recognise that key concepts integral to palliative care philosophy, such as 'home' and 'family', have been conceptualized from a Western perspective and may not have resonance with all communities. This doesn't mean that palliative care cannot be of benefit, just that it is likely to look different for different people.

Remember equity work is a process, not an outcome, and takes time

Trusting relationships take time to build and maintain. This investment is important to gaining the support of communities and working towards meaningful and sustainable change. Not investing time and pushing forward with your agenda can actually be harmful to the communities you are trying to help.

Always take a strengths-based approach

Acknowledge the strength, resilience and creativity of people who experience structural disadvantage. Don't start with 'what is the problem', particularly when this is conceptualized through the lens of your own perspectives and experience. Recognise the expertise of people with lived experience.

Understand intersectionality and diversity

Recognise that people's experiences are shaped by various aspects of their social position, not limited to one factor. Communities are complex and diverse: what may effectively address challenges within one community might not necessarily apply to another.

Take a structural focus

Understand and acknowledge the impact of systems of oppression such as colonialism, racism, ableism, homophobia, transphobia, sexism and ageism. This locates the problem in structures and moves us away from solutions which focus on rescuing, fixing, and sometimes blaming, the individual.

Recognise, and educate yourself about, trauma-informed approaches


Given the frequent occurrence of multiple traumas among individuals facing structural disadvantages, it is imperative to adopt trauma- and violence informed approaches in every interaction.

Acknowledge that this is emotionally demanding work

Equity work involves reflexivity and resilience. Being vulnerable, and humble, is key. It's important to constantly revisit the question of whether you are the right person to be working with this person, whānau/family or community.

Take action

All equity work must be action orientated. It is imperative to leave something positive and tangible as an outcome of the work. Commit to leveraging your own power and privilege to drive action that leads to improved outcomes for underserved communities. Crucially, this action must be informed and guided by the communities you engage with.



“Anō nei he pōhutukawa kōrua, e whātoro ana I ōno here.
Ki ōna takiaho. E hī au te kaha”

*Just as the pōhutukawa (tree), whose roots seek out those of it's
kind to be strong, So must we cling to each other.*

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