

The need for palliative care in Aotearoa New Zealand

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ABSTRACT

Death is inevitable. Dying is a whānau/family, social, spiritual and cultural experience, not just a medical event. A lack of access to holistic palliative care services in Aotearoa New Zealand means a good death may be out of reach for some.

The population in Aotearoa New Zealand is ageing and the number of deaths is set to roughly double in the next 30 years. The current stretched resources to care for people who are dying are not sufficient to meet this increase in need.¹

Palliative care is a human right, with laws in many European countries ensuring comprehensive delivery.^{2,3} Despite palliative care teams offering high levels of knowledge, skills and expertise, limited access to both generalist and specialist services undermines the overall care available. In particular, crisis support is limited.⁴

Comprehensive research shows that specialist palliative care not only improves quality of life but makes significant savings in health-care spending by reducing unwanted and inappropriate medical treatments.⁵

This paper outlines the current challenges in palliative care provision in Aotearoa New Zealand and key reasons why it is imperative that palliative care delivery is appropriately resourced and developed to ensure everyone in Aotearoa New Zealand has access to quality care at the end of their lives.

What constitutes good palliative care

Health New Zealand – Te Whatu Ora describes palliative and end-of-life care as providing *“people facing life-limiting conditions with holistic support and services based on the needs of the person and their family”*, stating, *“this care is essential”* and *“it is appropriate at any age and at any stage in a serious illness, and it can be provided alongside curative treatment.”*⁶

Palliative care in Aotearoa New Zealand aims to:

- optimise peoples' quality of life until death by addressing their physical, psychosocial, spiritual and cultural needs
- support the individual's family, whānau and other caregivers where needed into bereavement⁶

Specialist palliative care has consistently shown benefits in improving quality of life, being cared for in the person's place of choice⁷ and extending life.⁸ The research is so comprehensive that researchers have asked: what more information do funders need in order to properly resource palliative care?⁹

The core minimum for a specialist palliative

care team is a specialist doctor, registered nurse and social worker (all with specialist training in palliative care).¹⁰ Good-quality community palliative care requires properly trained staff and 24/7 availability.¹¹ Neither trained staff nor 24/7 availability are comprehensively provided in Aotearoa New Zealand.^{12,13}

Good palliative care provision requires collaborative work between specialist palliative care and generalist providers including hospital staff, general practitioners (GPs), community nurses, allied health, paramedics, community groups and volunteers. These services are under intense pressure, meaning access to generalist palliative care is becoming increasingly limited.⁴

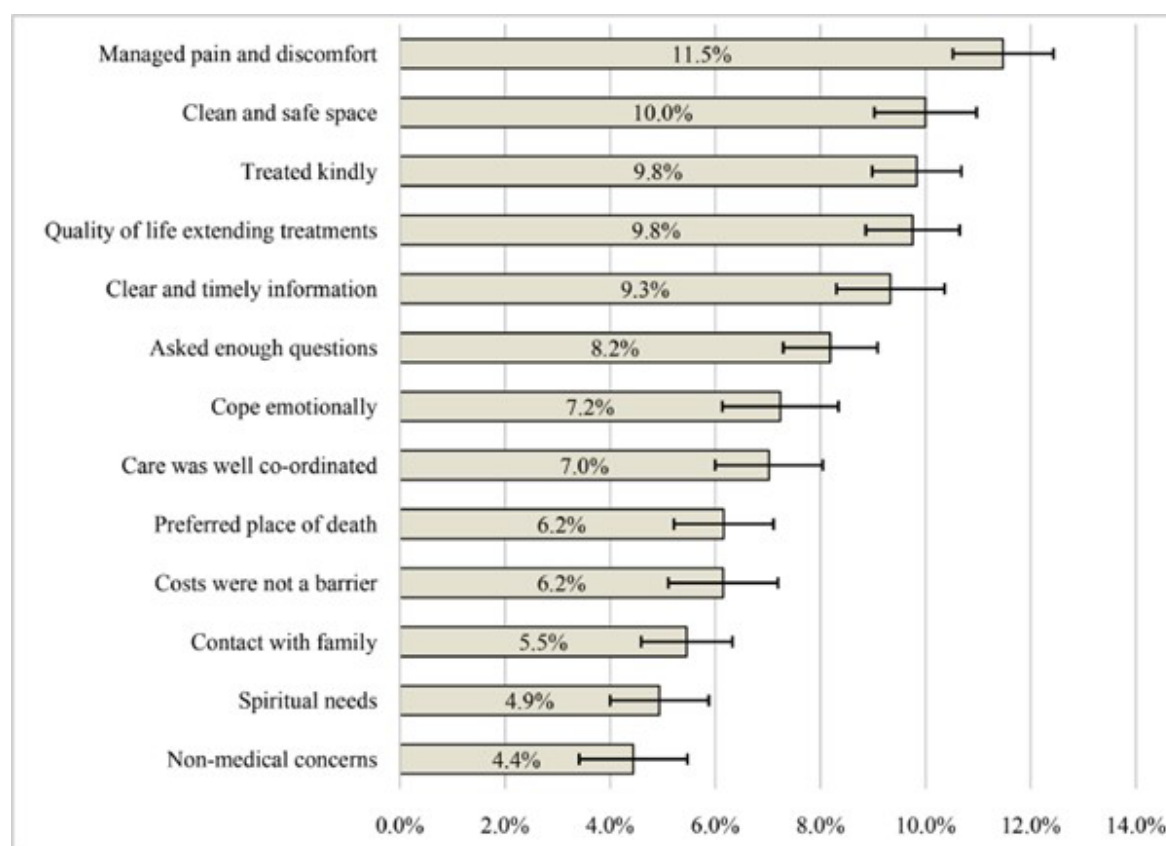
The minimum standards of provision for specialist and generalist palliative care are not being met in Aotearoa New Zealand.

What's important to people at the end of their lives

International research showed that managed pain and discomfort was rated as most important by bereaved families, closely followed by clean and safe spaces and being treated kindly.

Similarly, in an Aotearoa New Zealand survey, experiencing suffering, family/whānau concerns and symptom management were among the top

Figure 1: An international study showing what bereaved families rated as the most important factor when their relative was dying.¹⁴



five considerations. The least worrying aspects were funeral/care costs, place of death, cultural, religious and spiritual values and equipment.⁴

Evidence has shown that the top-rated concern at end-of-life is physical suffering. Access to services to relieve this are not available equitably across Aotearoa New Zealand.

The human rights imperative

In 2022, the World Health Organization Director-General Dr Tedros Ghebreyesus formally urged heads of state to integrate palliative care into their health systems and “face this global challenge on palliative care with collective compassion.”¹⁵

Aotearoa New Zealand is a signatory to numerous international treaties that recognise the right to health. Obligations include respecting the right to health and to not deny or limit equal access to preventive, curative or palliative health services. These obligations include providing non-discriminatory access to essential medicines and health facilities, especially for vulnerable or

marginalised groups.¹⁶

Palliative care is particularly crucial for marginalised groups, including those in rural locations. These groups often face significant barriers to accessing high-quality care, such as cultural misunderstandings, financial constraints and a lack of localised services.¹⁷ Ensuring equal access to palliative care is not just a matter of healthcare policy but one of social justice.

Ensuring paediatric palliative care is a human rights obligation. The United Nations Committee on the Rights of the Child states, “children are entitled to quality health services, including prevention, promotion, treatment, rehabilitation and palliative care services.”¹⁸ The one fully funded government specialist paediatric palliative care unit is in Auckland and is insufficient to meet the needs of all of Aotearoa New Zealand.¹⁹

Palliative care is a human right to which Aotearoa New Zealand is a signatory. Aotearoa New Zealand is not currently fulfilling those requirements.

International legislative progress

As an international example, while Portugal and the United Kingdom (UK) made significant strides in legislating palliative care as a human right, Aotearoa New Zealand is experiencing a lack of resources and infrastructure. Portuguese legislation led to the creation of the National Network for Palliative Care to provide active and comprehensive care to patients and their families.²

In the UK, the *Health and Care Act 2022* placed a duty on integrated care boards to commission and oversee palliative care services. The National Health Service England has funded the development of seven regional palliative and end-of-life care strategic clinical networks to support commissioners. A national call for change in palliative and end-of-life care came from academic and industry stakeholders, patients and carers. Considered essential were: the provision of 24-hour, 7-days-a-week specialist community palliative care support; education and communication skills training for health and social care professionals; and investment in community care to reduce unnecessary hospital admissions.²⁰

In Aotearoa New Zealand, multiple private members' bills to improve access to palliative care have been submitted to the ballot, with the most recent being in October 2024. However, none of these have ever been selected to be debated in Parliament.

While international progress has been made by legislating for palliative care provision, Aotearoa New Zealand has lagged behind and has not legislated for this essential service.

The economic case for palliative care

In addition to the ethical imperative, there is a strong economic case for investing in palliative care. A multitude of studies have shown that specialist palliative care is not only high value and cost effective, but it is in fact cost saving, reducing overall expenses in healthcare. The savings have been shown in communities and hospitals for cancer and non-cancer diagnoses. Healthcare costs for people with metastatic cancer were found to be 25% less if they had specialist palliative care consultation and 32% less in those with the highest level of comorbidity.²¹

Palliative care is an essential service that not only improves quality and potentially length of life

but also saves money from the overall healthcare budget. Aotearoa New Zealand would benefit from similar cost-saving measures, particularly as the population continues to age and the demand for palliative care services increases.

Who needs palliative care?

Expected deaths are those with a predictable trajectory through a chronic disease process, requiring a palliative approach to their care. It is estimated that 90% of deaths are predictable. One-fifth of hospitalised inpatients in Aotearoa New Zealand have been shown to meet criteria for palliative care input.²²

There were 37,884 deaths in Aotearoa New Zealand in 2023: 34,096 of these required a palliative approach to their care. The number of people requiring palliative care is increasing rapidly each year as age and complexity increase.

Of those requiring a palliative approach, 63.03–81.87% need specialist palliative care.²³ This need is variable in nature, from non-contact advice to comprehensive and intense care. Therefore, between **21,490 and 27,914** people required specialist palliative care in 2023 in Aotearoa New Zealand. Hospices in Aotearoa New Zealand were involved with **10,800** people, less than half of the required number to cover this need.

Specialist palliative care services were originally cancer orientated; however, the paradigm has now shifted to provide care based on need rather than prognosis or diagnosis. Palliative care services look after people with a range of diagnoses, including organ failure and frailty. Increasingly, people with dementia are receiving and will increasingly require palliative care.

Palliative care services should be available to people of all ages, with specialist services being available to all ages, including children and young people.¹⁹

Despite extensive work by non-governmental organisations, currently Aotearoa New Zealand specialist palliative care services are reaching less than half of those that need it.

How is Aotearoa New Zealand doing?

The international rating of palliative care in Aotearoa New Zealand has slipped from third in 2015 to 12th in 2021.¹⁴ Our rating lies below those of Costa Rica, Lithuania, Mexico and Slovenia.

Palliative care initiatives have often been grassroots led and locally driven. This has led to geographical inequities in funding and service delivery.

In contrast to other health services, only half of the funding for hospice services is provided by the government, while the rest is funded through fundraising and donations.

The only fully government-funded specialist services for children are offered at Starship Hospital in Auckland. Other partial services have been set up in other geographical areas, but they are not fully government funded, nor do they contain the full multidisciplinary team.¹⁸

The 2024 Health New Zealand – Te Whatu Ora Palliative Care National Survey showed specialist palliative care was highly rated by responders, with hospice as the highest rated provider of good or excellent care overall (94.8%). Access to GPs was limited and costly, with strong feedback on lack of available services in a crisis, particularly after-hours.⁴

It has been reported that clinicians in Aotearoa New Zealand treat people with dignity and respect while they are dying all, or most, of the time in the majority of cases, ranging from 88% for GPs to 99% for hospice doctors.⁴ Similarly, in a 2020 survey of bereaved people in the South Island, hospice care was rated most highly for overall quality of care, with GP and urgent care scoring lowest. Pain relief was also more effective as rated by bereaved relatives in hospice inpatient units compared with hospital, aged residential care and home.²⁴

Although specialist palliative care services are highly rated, they are inequitably available, understaffed and underfunded. Aotearoa New Zealand has slipped in international comparisons and will continue to do so unless palliative care is properly funded and staffed.

Challenges in palliative care delivery in Aotearoa New Zealand

Workforce and training

A critical issue in providing palliative care in Aotearoa New Zealand is the workforce shortages. The continuing shortages in staff with specialised

palliative care training and expertise is a barrier to high-quality provision.

Aotearoa New Zealand minimum standards state that every hospital must have access to a specialist palliative medicine doctor, with Category 1 hospitals having a minimum of one FTE on-site specialist nurse with postgraduate training in palliative care. Every Category 2 hospital should employ a minimum of one part-time nurse with palliative care as at least part of their designated role.²⁵ A 2016 survey showed specialist nurses were available in **less than half** of hospitals in the South Island, with specialist doctors available in **less than a third**.²⁵

International recommendations for numbers of specialist palliative medicine doctors range from FTE **2.0 to 4.4** per 100,000 population.²⁶ In 2024, the author surveyed the number of FTE for the specialist doctors in Aotearoa New Zealand and found it was currently 44.78. Unfilled vacancies stood at around 25%. This gives a population ratio of FTE **0.84** per 100,000, less than a half to a quarter of the international recommended level.

It should be noted that over 25% of this FTE is provided by doctors over 60 years of age, who can be predicted to retire within the next 5–10 years. Workforce predictions show that the number of specialist doctors will continue at the current numbers over the next 10 years unless action is taken to increase numbers. As the population ages and the death rate increases, the recommended workforce will be expected to rise as the intensity of need for palliative care services increases.

A 2019 Canadian model of specialist palliative care staffing uses a multidisciplinary approach to care, presuming that 15% of deaths require no palliative care and that GPs will lead on 65% of community palliative care.¹⁰ Using this model, Aotearoa New Zealand requires 150 FTE specialist palliative care doctors, 378 specialist palliative clinical nurse specialists and 78 social workers. The current Aotearoa New Zealand FTE equivalent of specialist palliative care doctors is **less than a third** of the required number.

Generalist palliative care providers are under increasing pressure. It is estimated that the number of GPs per 100,000 New Zealanders

Figure 2: Current senior medical officer (SMO) workforce in palliative medicine.

	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-74	75+	Total
Full Time Equivalent (FTE)	3.90	6.10	10.30	9.20	3.50	9.38	2.40	0.00	0.00	44.78
Head Count, Practitioners with an APC, Inc. Retired	7	11	15	12	8	14	8	1	2	78

is projected to fall from 74 in 2021 to 70 by 2031, and with a higher pace of population growth could potentially fall to below 66. In comparison, the Australian Government Department of Health reported a national 2020 GP rate of 116 per 100,000.

Core competencies in generalist palliative care have not been developed in all healthcare specialities; therefore, capability and confidence in delivering generalist care in Aotearoa New Zealand are limited.

Specialist and generalist staffing in Aotearoa New Zealand is well below minimum international recommendations.

There is a pressing need for the government to invest in education and training programmes that will produce more specialists and upskill generalist providers to increase the overall capacity of the palliative care workforce. This is a high-quality investment and a potential cost-saving measure, and it promotes the long-term stability of the wider health system.

Urgent action to increase training and capacity is required.

Inequity in palliative care services

There is considerable evidence that access to palliative and end-of-life care is not equal. Reduced access is related to ethnicity, socio-economic deprivation, homelessness, imprisonment, learning disability, sexual orientation, age, gender identity, diagnosis, geographic location and socio-economic status.²⁷

In Aotearoa New Zealand, there is geographical inequity. Hospice services have grown up outside of government healthcare services, with government funding inequitably distributed across the country. Despite the 2013 Resource and Capability Framework setting out minimum standards for service delivery, this has not been implemented and minimum standards are not met nationally.

Populations with structural inequities face unique challenges in accessing palliative care. It is essential that services are particularly sensitive to those needs and that they are culturally sensitive and responsive to different traditions and values. Although a high-quality framework for delivery of culturally appropriate care for Māori, Mauri Mate, has been developed and utilised by hospices, this has yet to be rolled out by generalist palliative care providers.

There continue to be inequities in generalist and specialist palliative care delivery dependent on who you are and where you live. Although actions

are being taken by hospices to address this, continued and sustained effort is required to break down inequities of service delivery.

How our population changes will affect the need for palliative care

The number of deaths per year is predicted to increase by 148% in the next 20 years as the Baby Boomer generation ages. The number of deaths will overtake the number of births in the 2050s. This varies by region: the Northern Region will have the highest increase in deaths in the next 20 years, up 160%, and Te Manawa Taki will increase by 148%, Central by 138% and Te Waipounamu by 143%.¹

Deaths are rising faster than the population, with the population predicted to increase by 129% by 2073 and deaths by 182%. Commissioning for palliative care must be based on deaths and not population, because deaths are projected to increase much faster than the population.¹

Deaths of Māori as a percentage of total deaths are projected to increase from 12.6% in 2023 to 13.5% in 2043. The proportion of deaths of people of Asian heritage will more than double over the same period. Equity of palliative care delivery needs to be measured against the ethnicity of deaths and not the ethnicity of the population.¹

The number of deaths of people over 90 will double in the next 20 years, with a reduction of deaths in the under-69s. This is particularly noticeable in the Māori age groups, with numbers of deaths more than doubling in each category over the age of 75. In the very old (95+), the number will more than triple.¹

The causes of death are changing as people live longer. Cancer deaths peak around 65 years of age, with organ failures at 75. For those who live over mid-80s, frailty and dementia become the prominent cause of death.¹

The number of deaths in Aotearoa New Zealand will increase rapidly in the next 20 years. Unless dedicated resources are increased, the already stretched health and social services will not cope with the increasing need.

Crisis management

The availability of appropriately resourced generalist services with access to specialist advice is essential for good palliative and end-of-life care. Twenty-four-hour care as a minimum standard for people with palliative needs is widely recognised in policy documents within Aotearoa

New Zealand and has been a minimum requirement in UK since 2014. However, this is not available across Aotearoa New Zealand.

Where models of 24-hour, 7-day access to care have been implemented, evaluation reveals:

- improved outcomes and experiences for patients and their families and increased quality and standards of care
- improved access to hospice inpatient admission for patients requiring urgent transfer into a specialist palliative care bed on weekends and public holidays
- prevention of unscheduled, avoidable acute hospital admissions and emergency department attendance
- improved support for providers of general palliative care throughout primary and secondary care²⁸
- staff working out-of-hours may work in isolation and therefore require a greater level of competency than those working in teams during the week with greater support and supervision²⁹

Out-of-hours palliative care provision is vital but often unavailable. Specialist palliative care staff are not available in sufficient numbers; meeting current and future needs requires increasing the numbers of specialist palliative care staff

while increasing the support of generalists.

Urgent attention is required to ensure 24/7 palliative crisis management is available to those who need it. Where GPs and community nurses are not available, plans should be put in place to formally collaborate with other services such as paramedics, hospices and neighbouring services to ensure this care is provided.

Conclusion

In conclusion, the need for palliative care in Aotearoa New Zealand is urgent. The growing demand due to an ageing population, coupled with insufficient resources and workforce shortages, requires immediate action. To honour the dignity and rights of all New Zealanders, it is essential that the government invest in expanding and resourcing palliative care services to ensure equitable, high-quality care for everyone, regardless of location, ethnicity or socio-economic status.

By resourcing palliative care services, Aotearoa New Zealand can ensure that its citizens receive the compassionate, holistic care they deserve in their final days, respecting their dignity and improving the quality of life for individuals and their whānau. Palliative care is not only a medical need but a fundamental human right that must be available to all.

COMPETING INTERESTS

Author is Chair of Palliative Care Collaborative Aotearoa.
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