

# Position statement on palliative care in Aotearoa New Zealand, National Palliative Care Steering Group

September 2024

## Purpose of this position statement

1. This position statement outlines the thinking of the National Palliative Care Steering Group (SG) about palliative care services in Aotearoa New Zealand (NZ).
2. It is intended to inform the National Palliative Care Work Programme (Work Programme) and includes background information, as well as key definitions and an overview of equity considerations, system pressures, and population projections.
3. It also outlines the aims of the Work Programme which include ensuring we have an equitable and sustainable palliative care system that meets the current and future needs of patients, whānau-family carers, and communities, as well as the services that care for them.

## Background

4. All people in NZ should have access to a range of person and whānau centred quality palliative care health services, when and where needed, that are accessible and culturally, linguistically and spiritually appropriate. This includes services that support whānau-family in their caring and bereavement.
5. However, there is inequity in access to, experience of, and outcomes from palliative care services. These inequities are driven by a range of historic, structural, systemic, social, personal and geographical factors that result in people not receiving the health care they need.
6. A review of palliative care services was identified by Health New Zealand | Te Whatu Ora (HNZ) as a priority action in Te Pae Tata - Interim New Zealand Health Plan 2022<sup>1</sup>. The identified action is to:

*Develop a nationally consistent model for paediatric and adult palliative and end-of-life care that is integrated across primary and community health and strengthens the equitable provision of palliative care across Aotearoa (pg. 63).*
7. The Work Programme was initiated in July 2023 to support a nationally consistent approach to planning, funding, service delivery and outcomes.

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<sup>1</sup> Health New Zealand | Te Whatu Ora, Te Aka Whai Ora - Māori Health Authority. 2022. *Te Pae Tata Interim New Zealand Health Plan 2022*. Available from URL: <https://www.tewhatauora.govt.nz/whats-happening/what-to-expect/nz-health-plan>. Accessed 7 May 2024.

8. The SG was established by HNZ in August 2023 to provide oversight and guidance for the Work Programme and recommendations to HNZ for national service improvements.
9. Health New Zealand and the SG are committed to working in partnership with government agencies, providers of palliative care services (primary and specialist), consumers, hāpori Māori and communities to ensure palliative and end-of-life care meets the needs of all New Zealanders.
10. Work is informed by cross-agency and cross-sector input, national and international evidence, the lived experiences of people with palliative care needs and their whānau-families, and the priorities identified by communities.

## What is palliative care?

11. The World Health Organisation (WHO) defines palliative care as: *an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.* [10]
12. The SG's expanded definition of palliative care is based on a modified version of *The New Zealand definition of Palliative Care* published in 2007<sup>2</sup>. The SG believes that:

***In Aotearoa New Zealand, palliative care is an essential health service for people of all ages with a life-limiting illness which aims to:***

1. ***optimise people's quality of life until death by addressing their taha tinana (physical), taha hinengaro (psychological), taha wairua (spiritual), taha whānau (family), and cultural needs. In some cases, this care may extend the person's life***
2. ***support whānau-family, and other formal and informal carers, during caring and bereavement.***

***Palliative care health services:***

- ***are provided according to need, and may be suitable whether death is days, weeks, months or occasionally even years away***
- ***may sometimes be suitable alongside treatments that are being given aimed at extending life***
- ***are available wherever the person/whānau-family may be***
- ***are provided by all health care professionals in all care settings, supported where necessary by specialist palliative care services***
- ***are provided in such a way as to meet the unique holistic needs of people and their whānau-family.***

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<sup>2</sup> Palliative Care Subcommittee, NZ Cancer Treatment Working Party. 2007. *New Zealand Palliative Care: A Working Definition*. Health New Zealand | Te Whatu Ora. Available from URL: <https://www.tewhātuora.govt.nz/assets/For-the-health-sector/Health-sector-guidance/Specific-Life-Stages/Palliative/nz-palliative-care-definition-oct07.pdf>. Accessed 2 May 2024.

**Palliative care acknowledges that:**

- **patients are first and foremost people, whose response to having a life-limiting illness may be individual and personal**
- **people are part of whānau-family and/or other social networks that may be their most trusted sources of support, principal providers of care, and key decision makers**
- **dying is more than a health experience; it is important that people and their whānau-families are supported to uphold the cultural, spiritual and societal traditions that are important to them**
- **the importance of the person within their whānau-family structures endures after their death.**

## Who delivers palliative care?

13. Informal carers, such as whānau-family, are often the main provider of care and support to those facing a life-limiting illness. While many do this willingly, the physical, psychological and financial burden on informal carers can be high and prolonged. Additionally, many do not receive adequate information, education and support from health and social services during caring and bereavement.
14. Palliative care health services are delivered by all health care professionals in two ways:
  - a) Primary palliative care – is an integral part of standard clinical practice and is provided by all health professionals and organisations regardless of the service or setting (e.g. general practice teams, aged residential care facilities, home and community support services, hospitals). Most people who die (2/3) will have been cared for by their usual health care team.
  - b) Specialist palliative care – is only provided by those health professionals who have completed further training and deliver specialist palliative care as the core focus of their service (e.g. hospices, hospital palliative care teams). Approximately 1/3 of people who die will have been referred to specialist palliative care services if their needs couldn't be met within their usual health care team. Specialist palliative care services also provide advice and education to primary palliative care providers.  
  
(See Appendix 1 for more detailed definitions)
15. Social and community care providers also contribute important support to people and their whānau-families in palliative and end-of-life illness, especially those who have pre-existing relationships with whānau-families that are underserved by mainstream health services.

## Equity and palliative care

16. The SG have adopted the Ministry of Health | Manatū Hauora definition of equity<sup>3</sup>, which is:

*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.*

17. Te Tiriti o Waitangi (Article Two, Treaty of Waitangi, 1840) assures Māori right to retain tino rangatiratanga (chieftainship/self-determination) over contributing to palliative care policy, accessing palliative care, and care that aligns with their end-of-life aspirations, priorities, and cultural needs. Māori and whānau have the right to exercise their mana motuhake (self-autonomy and independence) over their end-of-life care preferences.

18. In NZ, there are several communities that are currently underserved by palliative care services. These may include, but are not limited to:

- those experiencing homelessness, poverty, incarceration, serious mental illness, or addiction
- members of our disability, rainbow, gang-affiliated, and refugee and migrant communities
- Māori and Pacific Peoples
- adults with non-cancer diagnoses including frailty or dementia
- children and young people
- those living in rural and remote locations
- those not enrolled with a GP or engaged with other health services

19. The impact of inequities on health outcomes is well established. The impact on people's experience of palliative and end-of-life illness can include:

- dying younger and in preventable or non-typical ways
- experiencing amplified suffering
- not accessing services at a level that matches their needs
- whānau-family not feeling supported during caring and bereavement
- not receiving culturally safe care
- less agency to determine their end-of-life experience<sup>4</sup>

20. New models of care need to meet the needs of communities currently underserved by palliative care services. This will require integration with other services including non-government non-healthcare organisations or groups who are already working closely with these communities.

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<sup>3</sup> Ministry of Health's definition of equity, 2019. Available from URL: <https://www.health.govt.nz/strategies-initiatives/programmes-and-initiatives/equity>. Accessed 24 September 2024.

<sup>4</sup> Te Ārai Palliative Care and End of Life Research Group, 2024. *The voices of underserved communities in palliative care*. Available from URL: <https://www.tewhatauora.govt.nz/assets/For-the-health-sector/Specific-life-stage/Palliative-Care/The-voices-of-underserved-communities-in-palliative-care.pdf>. Accessed 24 September 2024.

## System pressures

21. Hospices are the largest provider of specialist palliative care in the community. Their current challenges include:
  - increasing financial pressures
  - unsustainable burden on communities to raise additional funds
  - increasing demand for, and complexity of, patient and whānau care
  - inconsistent patient access to hospice care nationally
  - workforce challenges.
22. Similarly, primary palliative care services (such as aged residential care and general practice teams) that provide the majority of care to those facing life-limiting illnesses in the community, are experiencing many challenges including:
  - increasing financial pressures
  - increasing demand and complexity of patients
  - workforce shortages
  - staff time and training constraints to adequately address people's palliative care needs.
23. People and whānau-families affected by life-limiting illnesses also report difficulties accessing the services they need including:
  - ongoing monitoring and management of their illness and symptoms in primary care, including access to home visits and after-hours support
  - consistent and timely palliative care support in aged residential care (ARC), including management of escalating symptoms, access to psycho-social support, and communication with whānau-family
  - pro-active multidisciplinary care planning to manage expected deterioration and death in all primary palliative care settings
  - timely referral to specialist palliative care services when needed
  - access to specialist paediatric palliative care services outside of Auckland, Hamilton and Christchurch
  - access to specialist palliative care services in some hospitals
  - culturally and spiritually responsive end-of-life care
  - access to equipment and support services when being cared for in their own homes
  - adequate education and support (emotional, physical, and financial) for carers.
  - Access to timely and affordable care from general practice teams including out of hours care
  - Palliative care that is responsive to their unique needs.
24. These pressures are compounded by health workforce challenges that include:
  - limited palliative care undergraduate, postgraduate, and vocational training for health professionals (including regulated and unregulated workforces)
  - limited palliative care specialisation opportunities for training and employment

- insufficient Māori, Pacifica and other ethnic groups represented in the health workforce and in particular working in palliative care
- limited access to resources to support culturally and linguistically diverse (CALD) people and their whānau-families.

25. These existing system pressures will impact our service planning assumptions.

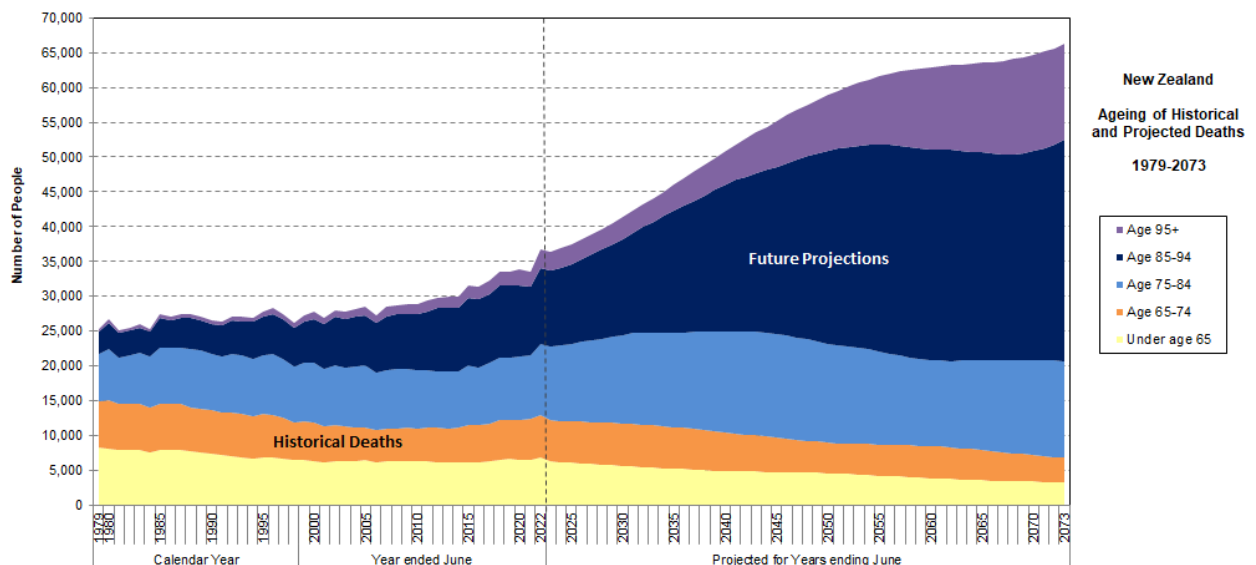
## Future projections of deaths and the potential impact on service planning<sup>5</sup>

26. Over 90% of all deaths in NZ are the result of a known life-limiting condition, which in most cases would benefit from receiving palliative care.

27. New Zealand has rapidly changing demographics of death. Population projections are clear that **the number of people dying in New Zealand each year will increase rapidly** (from approximately 36,000 in 2023, to 63,000 in 2053).

28. The number of deaths will exceed the number of births with the largest increase in **deaths at much older ages (85+ years)**. This is a major strategic challenge for NZ and global health sectors and will significantly impact the provision of palliative care.

29. Aging of deaths in NZ 1979-2073:



30. This increase in the number of deaths is due to changes in our population age profile. Over the next 20 years (2023-2043) this shift will result in many more people dying at older ages and includes a substantive increase in the number of Māori reaching, and dying at, older ages.

<sup>5</sup> McLeod, H. (2023). Planning for palliative care services in Aotearoa; what our population data tells us. Available from URL: <https://www.tewhatuora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/palliative/hui-planning-for-palliative-care-services-in-aotearoa-what-our-population-data-tells-us>.

31. The number of deaths in NZ is increasing faster than our population. Over the next 20 years (2023-2043) our population will increase by 115%, but deaths will increase by 148%. Therefore, commissioning for palliative care services must be based on the number of expected deaths, not on population growth.
32. This planning will also need to reflect the different age profiles of ethnic communities with equity of palliative care utilisation measured against the ethnicity of deaths and not the ethnicity of the population.
33. A further consideration for service planning is the higher likelihood that people at the end of their life will have multiple health problems due to deaths occurring at older ages. These could include organ failure, dementia, and frailty, which can make end-of-life care more complex and require more support from specialist palliative care providers.
34. Where people die (place of death) is an important indicator as it closely correlates to where people were cared for during their end-of-life illness and tells us where palliative care services are required the most. However, while place of death studies account for deaths in hospice inpatient units, they don't capture hospice care in other settings, such as private residence, ARC and hospital.
35. There are strong and persistent patterns by age and gender for the place of death. Public hospital and private residence both decline at older ages, with an increasing number of deaths in ARC.
36. The trend of increasing numbers of deaths in ARC has been a key feature of the last twenty years. It has long been the most likely place of death for NZ women and is now also the most likely place of death for those with cancer. It is close to becoming the most likely place of death for men (across all ages and causes of death).
37. Those living in rural or remote locations that need palliative care have less access to, and a lower usage of, ARC and hospice in-patient care. While place of death studies show they have a higher usage of private residence and other settings, this differs by region and degree of rurality.
38. **The impacts of these projections for future palliative care services will include:**
  - a) **the demand for palliative care services for older people will increase rapidly**
  - b) **the demand for specialist palliative care will also increase due to older people dying with multiple and complex health problems**
  - c) **more people will require care in the community (primary care) and in ARC.**
39. Future models of care will need to build capacity in both primary and specialist palliative care services and include an increased focus on those dying with the life-limiting conditions associated with ageing (e.g., dementia and frailty).

## **A way forward: The National Palliative Care Work Programme**

40. Health New Zealand's Work Programme was established in response to the need for a review of palliative care services for all New Zealanders. Guidance of this programme is provided by the SG.

41. The focus of the SG is overseeing the following key deliverables:
- providing recommendations on achieving equitable access to, and outcomes from, palliative care services for all New Zealanders
  - identifying and recommending core palliative care services that will be publicly funded
  - developing a national model for paediatric and adult palliative care
  - proposing national adult specialist palliative care service specifications and costings
  - providing recommendations to sustain a clinically and culturally competent, diverse workforce that represents the community it is serving and meets service demands
  - developing a national outcomes and reporting framework.
42. These deliverables are being achieved, in part, through the establishment of six short-term working groups including:
- Equity
  - Models of Care – Paediatric
  - Models of Care – Adult
  - Contracting and Funding
  - Workforce
  - Measures and reporting.
43. The SG will provide recommendations and proposals to HNZ as each deliverable is achieved.
44. All recommendations and proposals will demonstrate a commitment to Te Tiriti o Waitangi by aligning with the principles, as expressed in the Hauora Report Wai2575<sup>6</sup>:

***Tino Rangatiratanga / Self-Determination***

The principle of self-determination – this provides for Māori self-determination and mana motuhake. It requires the palliative care system to support by Māori for Māori approaches and services, and advocate for tino rangatiratanga to be enshrined within the wider system.

***Pātuitanga / Partnership***

The principle of partnership. This requires all parts of the palliative care system to work with Māori in the design, delivery and monitoring of all our mahi/work.

***Mana Taurite / Equity***

The principle of equity – this requires the palliative care system and providers to commit to achieving equitable health outcomes for Māori through all its functions.

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<sup>6</sup> Waitangi Tribunal. 2023. *HAUORA - Report on Stage One of the Health Services and Outcomes Kaupapa Inquiry*. Available from URL: [https://forms.justice.govt.nz/search/Documents/WT/wt\\_DOC\\_195476216/Hauora%202023%20W.pdf](https://forms.justice.govt.nz/search/Documents/WT/wt_DOC_195476216/Hauora%202023%20W.pdf). Accessed 7 May 2024.



***Whakamarumarutia / Active Protection***

The principle of active protection – this requires the palliative care system and all providers of palliative care to be well informed on the extent and nature of both Māori health outcomes and ways to achieve Māori health equity through culturally safe practice.

***Kōwhiringa / Options***

The principle of options – this requires the palliative care system and providers to ensure that all palliative care services are provided in a culturally appropriate way that recognises and supports the expression of Te Ao Māori.

45. Further information about the Work Programme is available on the HNZ website:  
<https://www.tewhatauora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/palliative/national-palliative-care-work-programme>

## Appendix 1: Palliative care definitions from the *New Zealand Palliative Care Glossary*<sup>7</sup>

**Primary Palliative Care:** [*sometimes referred to as generalist palliative care*] is provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team.

Primary palliative care is provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional.

In the context of end of life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of people with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. It is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses, and residential care staff etc. It is provided in hospitals by general ward staff, as well as disease specific teams – for instance oncology, respiratory, renal and cardiac teams.

Primary palliative care providers assess and refer people to specialist palliative care services when the needs of the person exceed the capability of the service.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of the person and family/whānau.  
(page 15)

**Specialist Palliative Care:** is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.

Specialist palliative care may be provided by hospice or hospital-based palliative care services where people have access to at least medical and nursing palliative care specialists (Palliative Care Subcommittee NZ Cancer Treatment Working Party 2007).

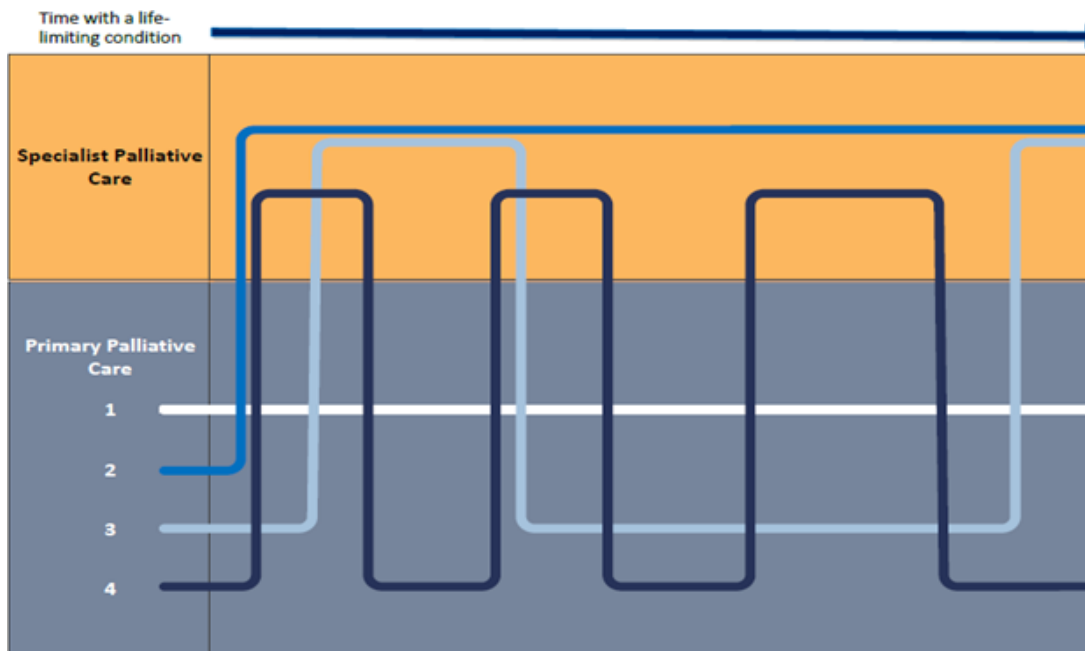
Specialist palliative care is delivered in two key ways:

- Directly – to provide direct management and support of the person and family/whānau where more complex palliative care need exceeds the resources of the primary provider. Specialist palliative care involvement with any person and the family/whānau can be continuous or episodic depending on the changing need. Complex need in this context is defined as a level of need that exceeds the resources of the primary team – this may be in any of the domains of care – physical, psychological or spiritual.
- Indirectly – to provide advice, support, education and training for other health professionals and volunteers to support the primary provision of palliative care.  
(page 16)

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<sup>7</sup> Ministry of Health. 2015. *New Zealand Palliative Care Glossary*. Wellington: Ministry of Health. Available from URL: <https://www.tewhātuora.govt.nz/publications/new-zealand-palliative-care-glossary>. Accessed 2 May 2024.

Figure 3: The relationship between primary palliative care and specialist palliative care



In Figure 3, episodes of care meet the needs of the person, family /whānau/ carers, depending on the expertise and experience of the primary palliative care providers. Four examples are illustrated.

- 1) All care is provided by the primary palliative care providers with no input required from specialist palliative care services.
- 2) Care is provided by specialist palliative care for the duration of the illness with little or no input from primary palliative care providers.
- 3) Initial involvement from specialist palliative care to guide a plan of care with re-referral during the deteriorating phase or during the last days of life.
- 4) Multiple episodes of specialist palliative care involvement during times of increased need/complexity, not necessarily during the last days of life.

3) and 4) are examples of the ways in which care may be provided intermittently by specialist palliative care in combination with primary palliative care. Continuity of care is provided by the primary palliative care provider(s).

**Specialist Palliative Care Service:** a team or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team. (page 17)