Health New Zealand
Te Whatu Ora

Proposed National Model for Integrated Adult Palliative Care in Aotearoa New Zealand

Have your say at: ThoughtExchange

https://tejoin.com/scroll/725835077

The Health Zealand | Te Whatu Ora, National Palliative Care Steering Group are now seeking sector, stakeholder and public feedback on this Proposed National Model for Integrated Adult Palliative Care in Aotearoa New Zealand, developed initially by our Models of Care – Adult Working Group and revised by Te Whatu Ora.

All feedback will be considered however, we would particularly appreciate thoughts on the following.

- **Primary Palliative Care** - What is good about the core components? What part(s) need improvement? How satisfied are you with them?
- **Specialist Palliative Care** - What is good about the core components? What part(s) need improvement? How satisfied are you with them?
- **Overall Model** - What do you think is good about the proposed model as a whole? What needs improvement? How satisfied are you with this as a future model?
- **Thought Exchange question** - What is the most important change you believe is needed to improve palliative care services for all adults in Aotearoa New Zealand?

Feedback is open now until 10 October 2025

ThoughtExchange is our preferred way to receive feedback from groups and individuals, this ensures that all submissions are considered and analysed together. Alternatively, feedback can be emailed to us at palliativecare@tewhatuora.govt.nz

We acknowledge the sensitive, and often challenging, nature of palliative care and appreciate your willingness to share your feedback.

For further information about the National Palliative Care Work Programme, see our website National Palliative Care Work Programme – Health New Zealand | Te Whatu Ora

ThoughtExchange survey

ThoughtExchange is a sophisticated AI-powered survey and engagement platform. It is designed to help organisations, like Health New Zealand | Te Whatu Ora, gather meaningful input from large numbers of people and groups, and quickly analyse the results to drive informed decision-making.

There are 2 sections in ThoughtExchange:

1. **Survey** – this first section asks specific questions about you and your views on the core components of both primary and specialist palliative care, as well as the overall model. Your responses will not be shared with other participants.
2. **Exchange** – this second section allows you to share an **unlimited number** of 'thoughts' about the Exchange question. These thoughts will be shared with other participants, but not your/your group's identity. At the end, you will be asked to rate thoughts shared by others.

Tips for using ThoughtExchange:

- You may want to have this document open in a different tab so you can refer to it while completing the survey and exchange.
- Avoid jargon, technical terms or names of people.
- At the end, you will be asked to read and rate thoughts that others have shared.
- You do not need to rate all thoughts, though it's recommended to rate at least 20.
- The number of thoughts appearing will increase as more people participate, you are welcome to return later to see what other thoughts have been added.
- This Exchange is anonymous. Your thoughts will be shared with other participants, but not your identity.
- Any identifying or harmful contributions will be automatically moderated and/or removed. You can also flag any thoughts you consider inappropriate.

Additional tips for groups using ThoughtExchange:

If you wish to put in a response from a group, organisation or network, you may want to collate your answers first and then add them once they are finalised. To do this:

- Nominate a lead person to respond on behalf of your group.
- Discuss the proposed model and questions with your group and decide what feedback you would like to share, and where you will enter it.
- There is a 1000-character limit for each of the 6 comment boxes in the survey (a total of approx. 3 pages), and 300-character limit for each 'thought' in the Exchange (unlimited).
- When asked to rate thoughts shared by others, rate these based on how your group would likely respond.
- Your group members can also submit individual feedback if they wish.

Proposed National Model for Integrated Adult Palliative Care in Aotearoa New Zealand

Models of Care – Adult Working Group

August 2025

Te Kāwanatanga o Aotearoa
New Zealand Government

Health New Zealand
Te Whatu Ora

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Acknowledgements

The content of this paper was developed by the Models of Care – Adult Working Group, a Working Group of the National Palliative Care Work Programme, between July 2024 and January 2025.

The group consisted of eight members from the wider palliative care sector, including representatives from hospice, hospital palliative care, primary care and aged residential care and included tangata whenua (Māori) perspectives. This work was supported by the Equity Working Group, the National Palliative Care Steering Group, and Health New Zealand | Te Whatu Ora (Health NZ) to finalise the proposed model and approach.

Health NZ gratefully acknowledges the thoughtful and expert input from Working Group members, as well as the support from others, including the Australia New Zealand Society of Palliative Medicine (ANZSPM).

Special acknowledgments also go to the co-chairs of the Working Group, Louisa Ingham and Hinetewai, for their skilled leadership, and to the subcommittees who developed elements of the work and the Guiding Principles graphic.

Contents

Executive summary

This paper proposes a new national model for integrated adult palliative care in Aotearoa New Zealand. It was designed to build on previous work and improve the experience of care for people and their whānau affected by life-limiting conditions. Responding to the growing need for consistent, accessible, and culturally safe care across the country, the proposed model aims to improve coordination, equity, and the quality of palliative care by aligning services around shared principles, clear roles, and robust support systems. It emphasises integration across all levels of care, with equitable outcomes for Māori, Pacific Peoples, rural communities and other underserved groups.

Grounded in seven Guiding Principles, the model is person- and whānau-centred, supports self-determination (mana motuhake), and improves equitable access to, and outcomes from, palliative care services for all New Zealanders.

The proposed model prioritises early intervention, holistic support, and proactive care planning in all care settings. At the core of the model is an understanding that the majority of people will receive their palliative or end of life care from nonspecialist services, such as general practice teams, aged residential care facilities, home and community support services, and hospital services.

The role of specialist palliative care services is to add an additional layer of support and expertise for people and/or their usual health teams, to manage palliative or end of life care for those with the most complex needs.

Also central to the model is improved collaboration and integration between all palliative care services with flexible and seamless transitions between care settings and across traditionally established geographic and service boundaries to best meet the needs of people and their whānau. This includes clear referral pathways, communication channels, collaboration agreements, consistent regional and national approaches, as well as increased engagement with communities to support locally responsive services. Rongoā Māori (traditional healing system) is also a vital part of holistic palliative care for Māori.

This model aims to improve quality of life, reduce inequities, and ensure that all New Zealanders can access high quality, holistic, culturally responsive, person- and whānau-centred, and seamless care at the end of life.

Once finalised, this model will guide service design, funding, and workforce development at national and regional levels, ensuring coherent delivery that meets current diverse needs as well as the future needs of our increasing and aging population.

Proposed National Model for Integrated Adult Palliative Care in Aotearoa New Zealand

1. Introduction

Palliative care in Aotearoa New Zealand is at a critical juncture. Increasing demand, growing complexity, and inequities in access and services highlight the need for a national, integrated approach. This national palliative care model is designed to improve the experience of care through enhanced coordination, ensuring consistent service quality, and embedding cultural responsiveness. It identifies the core components for both primary and specialist palliative care services and operates on a collaborative and flexible framework, ensuring that every adult with a palliative diagnosis, and their whānau, receives the appropriate level of care and support based on their needs. The model is designed to deliver care across all health care settings, involving both primary and specialist palliative care services. Seamless care transitions are achieved through excellence in collaboration, coordination, and communication between services. There is a strong emphasis on providing care that is culturally responsive, whānau-centred and rongoā enhanced, to maintain and maximise quality of life for people and their whānau.

The key differences between this model and our existing services are increased emphasis on:

- Holistic care that aligns with people's goals and includes support for whānau carers
- Integration of primary and specialist palliative care services with flexible transitions
- Proactive and collaborative care planning for the end of life
- Regional and national approaches to ensure consistent and equitable access to, and outcomes from, palliative care services.

This model forms part of the wider National Palliative Care Work Programme[1] which aims to develop nationally consistent approaches to paediatric and adult palliative and end-of-life care planning, funding, service delivery and outcomes. Key issues previously identified by the National Palliative Care Steering Group[2], who oversee the programme, include:

- 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). This is a major strategic challenge for New Zealand[3]. (See Appendix A for further information on projections of deaths)

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[1] https://www.tewhatuora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/palliative/national-palliative-care-work-programme

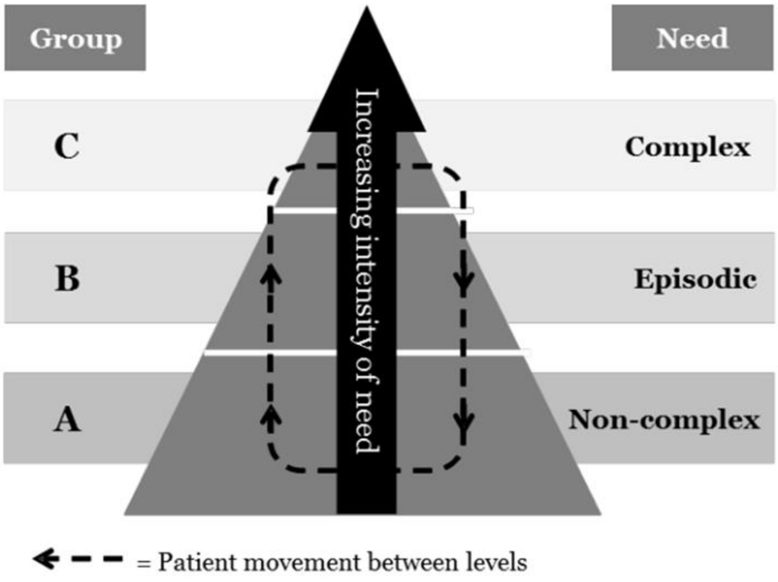
[2] https://www.tewhatuora.govt.nz/assets/For-health-professionals/Clinical-guidance/Specific-life-stage/Palliative-care/FINAL-Position-statement-National-Palliative-Care-Steering-Group-September-2024.pdf

[3] 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

- 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) more people will require care in the community (primary care) and in Aged Residential Care (ARC).
    c) the demand for specialist palliative care will also increase due to older people dying with multiple and complex health problems.
- 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).
- 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, cultural, social, personal, and geographical factors that result in people not receiving the health care they need.
- New models of care [also] 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.

Specialist services for complex needs

Our health services need to work as effectively and efficiently as possible while ensuring people can access the care they need. To do this, our specialist services are best kept for those with the most complex health needs. For palliative care, this is reflected in the levels of need identified in the Resource and Capability Framework[4] as included below (see Appendix B for further information about levels of need).



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[4] https://www.tewhatuora.govt.nz/for-health-professionals/clinical-guidance/specific-life-stage-health-information/palliative/palliative-care-publications

This ensures most people (who will experience normal, or non-complex, dying), can continue to be cared for by their usual health team(s) while the minority of people (who experience the most complex symptoms in their palliative or end-of-life illness), receive input from specialist services. This may require some specialist services to increase the support they provide to other health teams.

Increasing demand for palliative care

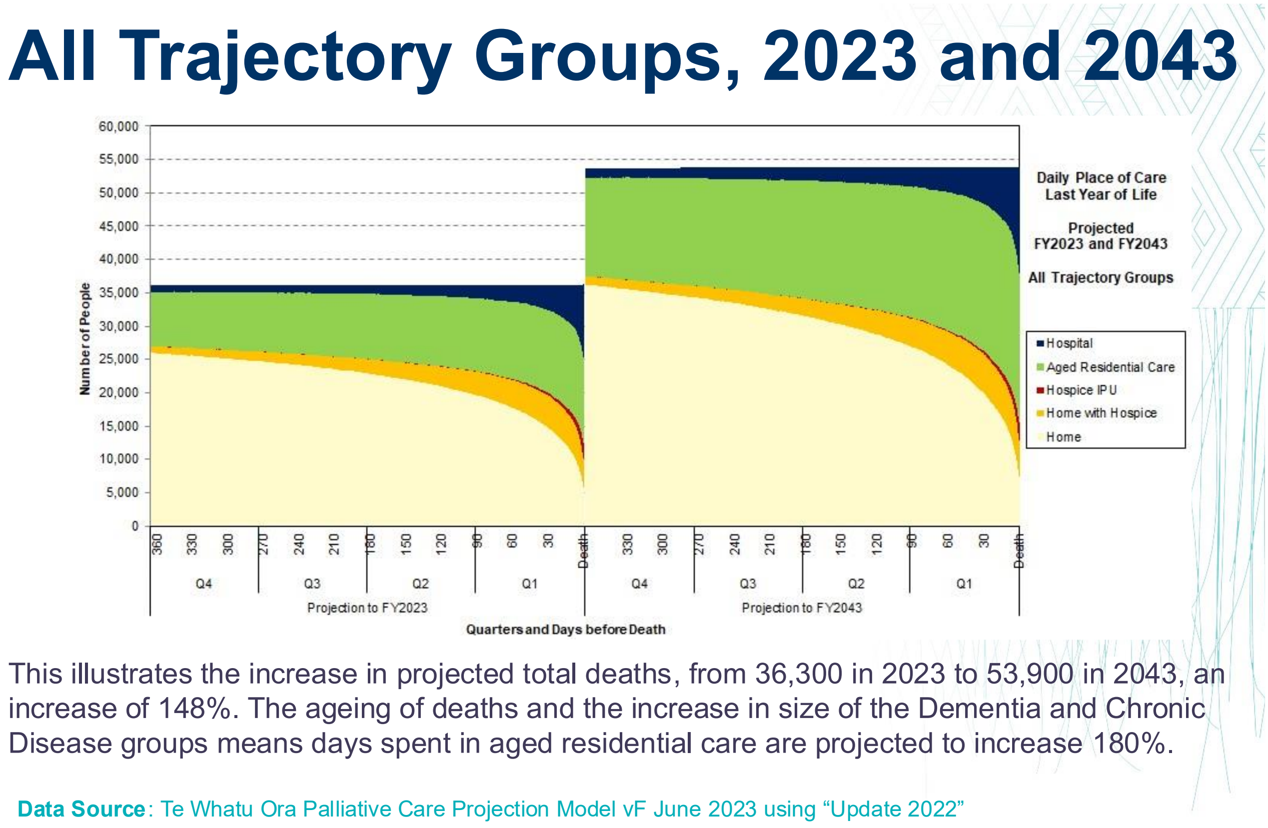
At present, it is estimated that primary palliative care services care for approximately ⅔ of people who die in NZ, while specialist palliative care services have input in the care of approximately ⅓ of people. Some people will receive care from both, in a shared-care or episodic care model.

Based on death projections, the demand for palliative care is therefore likely to increase as follows over a 30 year period:

Year	Total number of deaths	Number of people cared for by primary palliative care services	Number of people receiving input from specialist palliative care services
2023	36,000	24,000	12,000
2053	63,000	42,000	21,000

This represents an almost doubling of demand for care at the end of life across both types of services. However, these numbers do not consider the additional number of people who require palliative care input in the year(s) before their death.

Figure one below shows that most deaths will continue to occur in ARC, home or hospital settings, with only a very small number in hospice inpatient services.



All Trajectory Groups, 2023 and 2043

This illustrates the increase in projected total deaths, from 36,300 in 2023 to 53,900 in 2043, an increase of 148%. The ageing of deaths and the increase in size of the Dementia and Chronic Disease groups means days spent in aged residential care are projected to increase 180%.

Data Source: Te Whatu Ora Palliative Care Projection Model vF June 2023 using "Update 2022"

Figure 1 current and projected deaths by place of care

Increasing complexity due to deaths at older ages

In addition to increasing numbers of people dying in Aotearoa, population projections show a continual increase in the numbers of older people making up these deaths. This reflects the aging 'baby boomer' population entering their later years of life and advancements in health care that prolong life into older ages. As people age, they are more likely to experience disabilities and multiple long-term diseases, increasing the complexity of care they require at the end of their life. This impact is greater for Māori and Pacific Peoples who experience higher rates of chronic conditions at an early stage.

Aged Residential Care remains the expected place for end-of-life care and death for many people. This is followed by hospitals and homes. See Appendix A for further details.

Service disparities

Palliative care delivery is fragmented. While specialist services provide high-quality care, access remains uneven, particularly for Māori, Pacific peoples, immigrant/refugee, disability, and rural communities, and those with non-malignant conditions. The lack of a cohesive and current national strategy has led to regional variability in service provision with duplication in some areas and gaps in others, undermining quality and equity. These pressures are compounded by workforce shortages and insufficient coordination across care settings.

The proposed model offers a pathway for palliative care in Aotearoa. By embedding equity, integration, and whānau-centred values, it positions the health system to meet current and future needs with compassion, consistency, and cultural integrity. Through unified efforts across sectors and communities, every New Zealander can live and die well, wherever they are.

This work focussed on the palliative care needs of adults. Although an age range was not defined for the model, we acknowledge that the palliative care needs of adolescents and young adults are unique and specific.

Terms and concepts used in this paper

The table below gives a *general* overview of how key terms are used in this paper, as well as key concepts that support the work. For more detailed definitions of terms, please see Appendix B or refer to the New Zealand Palliative Care Glossary[5].

Palliative care	Holistic care provided by all health professionals in all care settings that focuses on reducing suffering and improving the quality of life of people and their whānau who are facing problems associated with life-limiting or life-threatening illness.
People	Consumers and service users in general.
Whānau	Family, in the broader sense.
Tāngata whenua	Māori people in general.
Mana motuhake	Self-determination, independence and authority.
Rongoā Māori	The traditional wellness system of Māori, inclusive of traditional medicines and practices.
Primary Palliative Care	General or non-complex palliative care delivered in any care setting by any healthcare professional as an integral part of standard clinical practice to support the normal dying process.
Specialist Palliative Care	Specialist or complex palliative care delivered by specific health professionals with additional expertise in palliative care.
Navigators / Kaiāwhina	A broad role encompassing aspects of case management, care co-ordination, patient education, and advocacy.
Identifying palliative care needs	People with deteriorating health due to serious illnesses or health conditions, or frailty, may benefit from palliative care. This should be driven by need, not by prognosis or diagnosis. Relevant tools[6] should be used by health professionals to identify people with palliative care needs.
Focus on quality of life	Wherever people are located, the core goal of palliative care remains; to enhance their quality of life, including managing symptoms effectively, promoting emotional well-being, and ensuring culturally meaningful care. Wherever this is relevant, quality of life will include access to rongoā healthcare.

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[5] https://www.tewhatuora.govt.nz/publications/new-zealand-palliative-care-glossary

[6] For example, the SPICT tool **https://www.spict.org.uk/the-spict/**

Promoting a palliative care approach	A “positive and open attitude toward death and dying by all service providers working with the person and their family and respects the wishes of the person in relation to their treatment and care”[7]. Services will ensure their staff foster and promote quality palliative care for all people that would benefit from this approach.
Proactive/advance care planning	Planning ahead is crucial to avoid unnecessary crises, as well as unwarranted and unwanted interventions. Skilful conversations about the future can also decrease stress and worry for people and support self-determination (mana motuhake) over their care. All care providers will ensure that people have the opportunity to discuss and document their wishes (for example in an Advance Care Plan and/or Shared Goals of Care document). Providers will also ensure that plans are honoured throughout the care journey, allowing for person/whānau-centred decisions as their condition changes or they move between different care settings. Where possible, culturally and linguistically appropriate resources should be made available.
Whānau involvement	Whānau are central to the care of most people and will be included in decision-making, care planning and care provision, according to their capacity and the wishes of the person. Cultural considerations, including access to rongoā healthcare and attending to the values of the whānau, will be fully integrated, especially at the end of life.
Support for whānau carers	Care providers will support and empower whānau to participate in caregiving. This includes ensuring timely access to training/education for whānau who wish to provide care at home. Supports and resources (such as equipment, home help, respite care and grief counselling) will also be available according to need.

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[7] New Zealand Palliative Care Glossary **https://www.tewhatuora.govt.nz/publications/new-zealand-palliative-care-glossary**

2. Guiding principles

The Working Group identified seven Guiding Principles for Palliative Care in New Zealand | Te Pou Tūhono mo te tiaki palliative i Aotearoa. These principles underpinned the development of the proposed model and are incorporated into the graphic (Figure 2) below.

Early Conversations | He Kōrero Māmā, He Hōhonutanga

Early and ongoing conversations with people and whānau, facing life-limiting illness. Respecting the patient's wishes and preferences, supporting their decisions about their care and end-of-life choices.

Needs-Based | He Hanga Rerekē

Care plans are tailored to individual and whānau needs, focusing on symptom management and aligned with their goals.

Culturally Responsive and Appropriate | He Tikanga Māori, He Ngākau Māori

All services must be culturally appropriate, with particular attention to the needs of Māori and whānau Māori.

Whānau-Centred | He Pātaka Whānau

People and whānau are at the centre of the care model and decision-making processes.

Funding Aligned to Patients | He Pūtea Āhei, He Āwhina

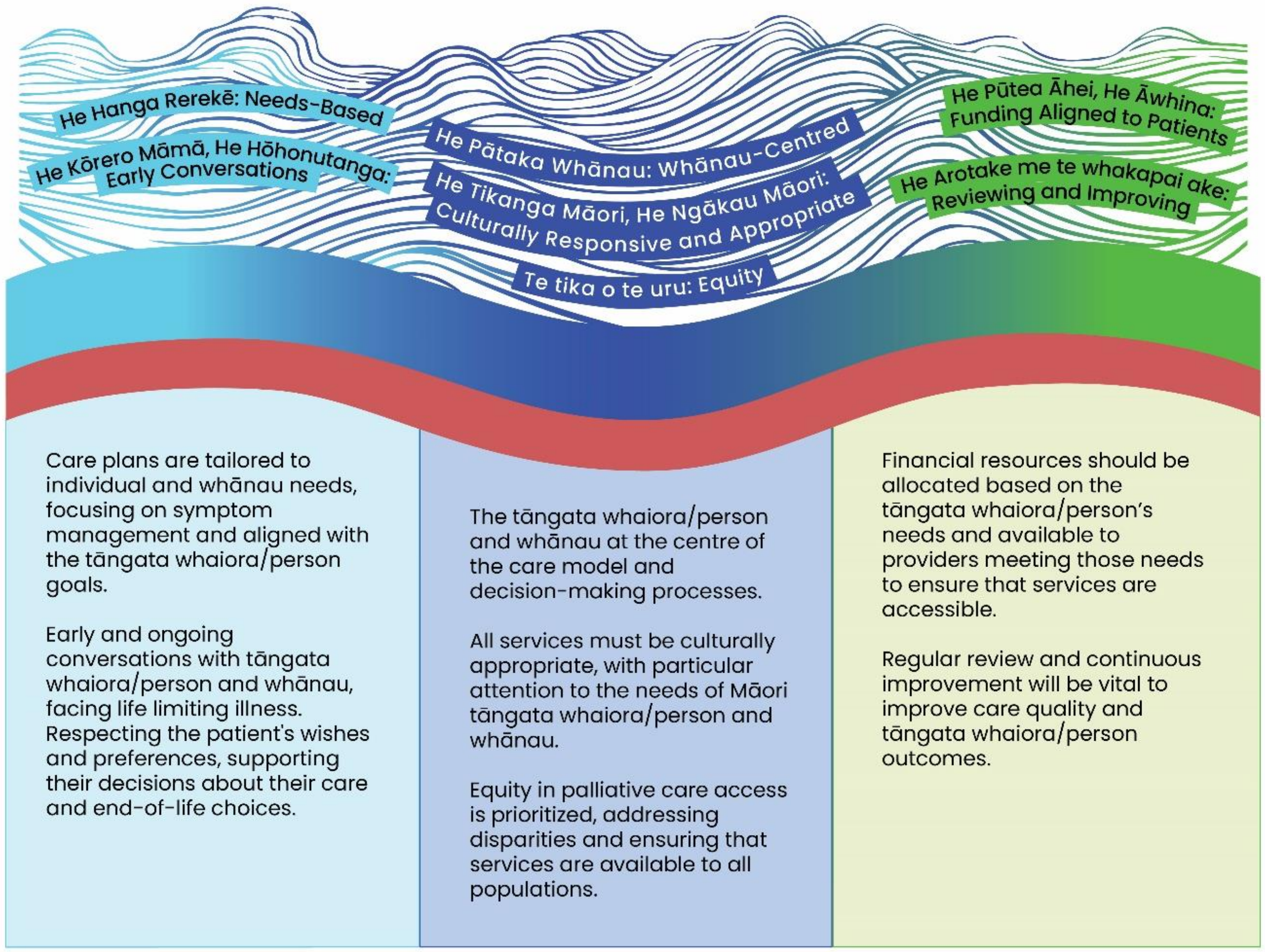
Financial resources should be allocated based on the needs of people and available to the services who are meeting those needs, to ensure that the right services are available and accessible.

Equity | Te tika o te uru

Equity in palliative care access is prioritised, addressing disparities and ensuring that services are available to all populations.

Reviewing and Improving | He Arotake me te whakapai ake

Regular review and continuous improvement will be vital to improve care quality and outcomes.



Care plans are tailored to individual and whānau needs, focusing on symptom management and aligned with the tāngata whaiora/person goals.

Early and ongoing conversations with tāngata whaiora/person and whānau, facing life limiting illness. Respecting the patient's wishes and preferences, supporting their decisions about their care and end-of-life choices.

The tāngata whaiora/person and whānau at the centre of the care model and decision-making processes.

All services must be culturally appropriate, with particular attention to the needs of Māori tāngata whaiora/person and whānau.

Equity in palliative care access is prioritized, addressing disparities and ensuring that services are available to all populations.

Financial resources should be allocated based on the tāngata whaiora/person's needs and available to providers meeting those needs to ensure that services are accessible.

Regular review and continuous improvement will be vital to improve care quality and tāngata whaiora/person outcomes.

Figure 2 2: Guiding Principles for Palliative Care in New Zealand | Te Pou Tūhono mo te tiaki palliative i Aotearoa.

A ka huri au ki te hunga Kākāriki – anei tātou kei mua I nga kaupapa o te ra nei, anei taku mihi aroha ki a koutou katoa.

This whakataukī speaks of the awa, the river, as an indivisible and living whole from the mountains to the sea, its tributaries and all its physical and spiritual elements.

The Working Group likened the palliative care journey to the natural flow of the river, how it changes over time, with many tributaries connecting to the main source as resources flowing in and out of the whānau journey, weaving the identified necessary support and care options as required. Likewise, the awa has varying currents and ever-changing directions, reflecting the nature of our experiences. Like the river with its twists and turns, life sometimes sweeps us gently along and sometimes the rapids come out of nowhere.

3. Core components, descriptions and responsibilities of palliative care services

A central requirement of this work was to identify and recommend core components of palliative care services to meet current and future demands. These were separated into:

- Core components of primary palliative care services
- Core components of specialist palliative care services

These should be read in conjunction with the service descriptions and responsibilities as well as information about collaboration between services to achieve accessible, seamless, and coordinated palliative care for adults affected by life-limiting illness. These core components, once finalised, will form the basis of future Service Specifications (contracts) for adult specialist palliative care services in the community.

3.1 Core components of primary palliative care services

For patients cared for in private homes, aged residential care facilities and in-patient hospital settings, providing a palliative approach to care is an integral part of the standard clinical practice delivered by all health professionals over the life course continuum. This approach is appropriate for the majority of people, who will experience normal dying with non-complex needs. The focus is on identifying care priorities, reducing suffering and enhancing the quality of life for people and their whānau.

This model prioritises 11 components that are whānau centred and team-based and address early intervention, holistic assessment, and ongoing support for both the person and their whānau.

Proactive/advance care planning and shared decision-making

- **Facilitation of conversations:** Early and ongoing discussions about future care preferences, ensuring people's wishes are documented and honoured following terminal diagnosis.
- **Documentation and accessibility:** Care plans (e.g., Advance Care Plans) documents should be easily accessible across the healthcare system.
- **Shared Goals of Care:** Ensure this communication tool, or its equivalent, is used effectively in ARC facilities and hospitals to ensure appropriate care is delivered at the end of life.

Holistic assessment and care planning

- **Initial and ongoing assessments:** Comprehensive evaluations are ideally conducted by a multidisciplinary team (MDT) that includes doctors, nurses, and other allied health professionals as appropriate. MDTs are not available in many primary palliative care settings, in which case treatment planning is undertaken by a lead clinician – usually the person's General Practitioner (GP) or a nurse working with that GP.

- **Individualised care plans:** Development of personalised care plans in collaboration with people and their families, outlining goals, preferences, and any advance care planning (ACP) considerations.

Symptom management

- **Comprehensive symptom control:** Access to effective pain management and treatment of other distressing symptoms using pharmacological and non-pharmacological interventions.
- **Regular monitoring:** Ongoing assessment of symptom relief effectiveness and timely adjustments to treatment plans.
- **Care in the dying phase:** Implementation and use of Te Ara Whakapiri: care in the last days of life (or equivalent), alongside specialist palliative care services as needed.

Whānau support and education

- **Involvement of whānau:** Recognising the importance of family in care, providing support and resources to empower whānau to lead the care process.
- **Support for whānau:** on caregiving, symptom management, and emotional support strategies.

Culturally responsive care

- **Cultural competency training:** Ongoing training for healthcare staff to understand and respect the cultural needs of Māori and other communities, ensuring culturally safe practices.
- **Incorporation of tikanga Māori where appropriate:** Collaboration with Māori health providers to integrate cultural practices into care for those who prefer services to be provided in this way.

Access to resources and supports

- **Aids and equipment:** Facilitation of access to necessary medical equipment and supplies to support home care and enhance comfort.
- **Personal care and carer respite:** Facilitation of access to personal cares and respite as needed.

Interdisciplinary collaboration

- **Team-based approach:** Coordination among healthcare professionals to deliver comprehensive care, led by the person’s enrolled GP, ARC coordinator, or another identified coordinator. Effective collaboration across multiple primary care providers (eg ARC, pharmacy, home and community support, and district nursing) will require development of tools, information systems and processes to link these disparate providers to deliver more coordinated care.

- **Effective communication:** Systems for sharing information among healthcare providers, people, and whānau to promote continuity and coherence in care.

Access to specialist support

- **Referral pathways:** Clear and efficient systems for referring people to specialist palliative care services when primary palliative care providers identify complex needs beyond their scope.
- **Consultation services:** Availability of advice from specialist palliative care teams to support primary palliative care providers in managing complex cases, including support out of hours.
- **Access to palliative care education:** to support ongoing staff development in primary palliative care.

Psychosocial and emotional support

- **Access to counselling services:** Provision of primary care level psychological support for people and whānau dealing with complex emotions surrounding life-limiting illness and end-of-life care (e.g. through access and choice services).

Community engagement and Compassionate Communities

- **Compassionate Community initiatives:** Support for local initiatives and programs to foster community involvement in supporting those with life-limiting illnesses. This component may be outside of the health funded services but is an important societal endeavour.

Quality Improvement and evaluation

- **Regular feedback mechanisms:** Establishing systems to collect feedback from individuals and whānau regarding their care experiences, and from referrers, to inform Quality Improvement initiatives.
- **Outcomes Measure:** Utilising evidence-based tools, such as patient experience measures, to track people’s outcomes, satisfaction, and adherence to care plans.
- **Participation in research:** Engagement in research initiatives to evaluate care practices to drive innovation and develop evidence-based practice for palliative care.

Primary palliative care service descriptions

People with non-complex/normal dying and/or stable needs will receive palliative care services from their usual care teams. These services provide palliative care as a component of their normal clinical care.

Services

The services who provide this include (but aren't limited to) general practice teams, community/district nursing, aged residential care (ARC), ambulance services, pharmacies, hospital and specialist services (e.g., oncology, nephrology, surgery etc, wards and out-patient services), Hauora Māori/iwi services, home and community support services.

Care settings

People may receive this care (in person or via telehealth) in private homes, ARCs, rural, secondary and tertiary hospitals, marae or other settings (e.g., prisons).

Skill sets

Services that provide primary palliative care should have access (e.g., via referral) to people with the skills to provide quality holistic care. This may include doctors, nurses, counsellors, social workers, spiritual support workers, allied health professionals, Māori support workers (or other cultural liaison roles), Kaiāwhina, healthcare assistants/carers, paramedics and other support roles.

Expectations of key primary palliative care services

Aged Residential Care

Aged Residential Care is currently the most common place of death for New Zealanders. This is expected to continue. Being able to provide quality primary palliative and end-of-life care for residents is an essential part of standard care in all ARC facilities. In cases where a resident's needs are more complex, facilities are expected to seek advice and support from their local specialist palliative care service. Aged residential care providers are required to have appropriate access to nursing and General Practice services for their residents at all times.

General Practice teams

General Practice teams play a vital role in supporting people in the community and in ARC (and other community inpatient facilities). The person's GP is responsible for providing medical assessment, treatment and care planning, and for coordinating access (usually via referral) to other required services.

As our population increases, and our demographics change, General Practice teams will have an increasing role in leading and co-ordinating primary palliative and end-of-life care for the majority of people who die each year. It is important that these teams are well prepared and supported to achieve this and can seek advice or direct input from their specialist palliative care services as required.

Some GPs provide services afterhours to support end-of-life care. Urgent and after-hours clinics provide in-person care afterhours, when GPs may not be available. In addition, people can now access 24/7 GP online care, through various approved providers.

Hospitals[8]

Many people affected by life-limiting or life-threatening conditions will require hospitalisation and many expected deaths in Aotearoa happen in our hospitals, especially where clinical concerns cannot be safely or timely managed in community settings. It is important that hospital clinical teams are well prepared and supported to provide quality palliative and end-of-life care in all hospital wards and have access to specialist palliative care advice, or direct input, when needed.

Community nursing services

Community nursing services, such as District Nursing, private nursing care agencies, primary care nurses and home-based support nurses, are a vital support for people at home. These services often build long term relationships with people affected by life-limiting conditions and increasingly provide palliative and end-of-life care at home. It is important that these services are well prepared and supported to achieve this and can seek advice or direct input from their local specialist palliative care service as required.

Ambulance services

Ambulance services provider episodic acute primary palliative and end-of-life care for people in the community. Their role is increasing as more people are supported to live and die at home (including in Aged Residential Care). Ambulance services also have a unique role in responding to escalating or acute symptoms after-hours, as one of the few services providing timely face-to-face clinical assessment in the person’s home, supported where necessary by advice (e.g., by phone) from specialist palliative care services.

Home and community support providers

Many people requiring palliative care will be receiving personal care and household management services from home and community support providers. These carers go into the individual’s home and can be a vital part of person centred primary palliative care. They are often not well connected into other clinical services.

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[8] While hospitals are secondary or tertiary services, they provide primary (or general) palliative care as part of standard clinical practice.

Key responsibilities of primary palliative care services

Note that it is recognised that the extent to which the following responsibilities can be carried out will depend on the resourcing available for palliative care in other settings.

Whānau-centred care

Primary palliative care focuses on the needs of people and whānau, establishing communication channels, developing culturally responsive care plans and priorities, and providing education, support and symptom management.

Holistic assessment and planning

Comprehensive, regular assessments of physical, psychological, social, spiritual, and cultural needs of people will be conducted and coordinated by primary palliative care providers. Individualised care plans (e.g., ACP and SGoC documents) will be created in collaboration with the person and their whānau and updated over time.

Symptom management

For non-complex symptom control and emotional support, primary palliative care providers will manage pain relief and other symptoms using pharmacological and non-pharmacological methods, including prescribing medications in anticipation of symptoms where appropriate. If symptoms escalate beyond the expertise of primary palliative care services, the person and/or their whānau, can be referred for advice or direct specialist palliative care input.

Whānau support and education

Primary palliative care providers will empower whānau carers by identifying their needs and offering education, information and emotional support. Carer respite services and home help services will be facilitated through local community services and healthcare providers. This may include referrals via HealthPathways (HealthPathways is an online decision support tool used by clinicians to help make assessment, management, and specialist request decisions.)

Referral pathways to specialist care

Clear pathways (such as HealthPathways) will be in place to enable timely escalation of care to specialist services if complex needs arise. Early intervention from specialists will be available for patients transitioning from non-complex to complex care needs.

Access to care and support out of hours

Services will have clear plans will be in place to ensure timely care out of office hours, including where, when, and how to access support and advice. These plans will include provisions for acute assessments and interventions to ensure appropriate symptom management for those with evolving needs, holistic concerns or those at the end of life. This may require effective collaborations between a range of services such as ambulance services, 24/7 GP online care providers, urgent care clinics, hospices, afterhours pharmacy, ARCs, local hospitals and other providers to ensure people receive appropriate timely care.

Care coordination

People and whānau receiving palliative care often require a lead clinician or co-ordinator, to provide a link with, and ensure seamless transitions between, services and/or care settings. Coordinators can facilitate the development of individualised care plans and end-of-life care plans in partnership with the person and their whānau. Care coordinators will promote timely access to resources and equipment to support care in the home.

The GP an individual is enrolled with, is responsible for providing medical assessment, treatment and care planning, and for coordinating access (usually via referral) to other required services. When a person is admitted to ARC, or is in hospital, then the hospital / facility is expected to coordinate access to services.

3.2 Core components of specialist palliative care services

Specialist palliative care services are an additional layer of support and expertise for the minority of people who will experience complex palliative care needs that exceed the expertise of primary palliative care providers. Specialist palliative care may be comprehensive, episodic or continuous and occur across a range of settings. People and their whānau eligible to access these services are those who would benefit from specialist palliative care input and meet current referral criteria[9].

Specialist palliative care is provided in addition to the care people will continue to receive from their usual health care team(s). People are discharged from specialist care when these services are no longer required.

The 10 components of specialist services focus on complex symptom management, complex psychosocial supports, and holistic care for people and their whānau.

Comprehensive holistic assessment

- **Interdisciplinary assessments:** Conducted by members of an interdisciplinary team that includes specialist trained palliative care doctors, nurses, social workers, cultural support workers, and allied health professionals. Assessment includes assessment of complexity of physical, social, cultural, psychological and spiritual need.
- **Care planning:** Clear outline of people’s goals and preferences, including proactive/advance care planning and incorporating cultural considerations such as tikanga Māori where applicable.
- **Initial and ongoing reviews:** Regular assessments to monitor physical, psychological, social, cultural, and spiritual needs, ensuring care plans are adapted as circumstances change.

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[9] Referral Criteria for Adult Palliative Care Services in New Zealand https://www.tewhatuora.govt.nz/publications/referral-criteria-for-adult-palliative-care-services-in-new-zealand

Ongoing follow-up care

- **Complex symptom control:** Expert management of complex symptoms using advanced pharmacological and non-pharmacological therapies.
- **24/7 access:** Specialist advice and interventions, including crisis management for acute complex issues.
- **Access to support and advice**: Expert backup for primary palliative care providers where they are leading the face-to-face care, including afterhours.

Individualised care plans

- **Collaborative care planning:** Development of personalised care plans in partnership with the person and their whānau, reflecting individual goals, preferences, and values.
- **Comprehensive end of life care plan:** for individuals in the last short weeks/days of life, detailing 24/7 access to nursing and medical assessment and care. As well as the service responsible for providing after-death documentation or certificates as required by law.

Complex psychosocial and emotional support

- **Psychological services:** Access to counsellors to provide additional emotional support for people and whānau when needed.
- **Grief and Bereavement Support:** Structured bereavement services for whānau to help navigate the grieving process, including individual and group counselling**.**

Education and support to primary palliative care services

- **Access and support**: Provision of support to primary palliative care services for the delivery of the palliative care approach, including afterhours.
- **Training programs for healthcare professionals:** Facilitation of nationally recognised education for healthcare professionals and carers to enhance skills in palliative care, symptom management, decision-making and communication.
- **Last days of life:** Education and support to implement a last days of life program e.g., Te Ara Whakapiri; care in the last days of life.

Access to specialist resources and supports

- **Aids and equipment:** Facilitation of access to necessary medical equipment and supplies to support home care and enhance the person's comfort.
- **Personal care**: Facilitation of access to personal cares and respite, if required.
- **Night care** Provision of night nursing in the person's own home in the last days of life as appropriate.
- **Carer education**: opportunistically as part of the ongoing follow-up, and through access to formal carers' courses.
- **Carer respite:** Facilitation of access to respite opportunities for carers if needed.

Access to inpatient care

- **Inpatient options:** Availability of inpatient services for people requiring complex symptom management or end-of-life care, supervised by specialist palliative care teams. Beds can be in hospices, or in hospitals, or ARC facilities where they are supported by a specialist palliative care team.

Coordinated care

- **Case management:** Designated trained palliative care coordinators to oversee people's care across various settings, ensuring seamless transitions between care settings.
- **Effective communication:** Systems for sharing information among healthcare providers, people, and whānau to promote continuity and coherence in care.

Audit, research, and Quality Improvement

- **Participation in research:** Engagement in research initiatives (local, national and international) to evaluate care practices to drive innovation and develop evidence-based practice for specialist palliative care.
- **Quality Audits:** Regular audits of service delivery against established national and international standards and utilising evidence-based tools to collect person/whānau -related outcome data to ensure service effectiveness and identify areas for improvement.
- **Participation in sector networks and forums:** Ongoing participation in sector discussions to progress palliative care service design, delivery and outcomes to ensure services remain fit for purpose.

Culturally safe care

- **Cultural liaison roles:** Designated Māori support workers and cultural liaisons to ensure culturally safe practices and support for Māori and whānau Māori.
- **Integration of tikanga Māori:** Respectful incorporation of Māori cultural practices and values into care plans and delivery.
- **Community relationships:** Connections and relationships with local communities are established and maintained to ensure their views and care needs are integrated into service design and evaluation.

Specialist palliative care service descriptions

People and whānau with complex symptoms, psychological or social needs will be referred to specialist palliative care services to provide an additional layer of support if their care needs exceed the expertise of their usual health care teams(s). For example, it may be necessary for specialist palliative care teams to support home-based, end-of-life care in the last days/short weeks of life. Specialist palliative care teams have advanced training in palliative care and focus solely on providing palliative care. It is expected that the case loads of specialist teams reflect those with the highest, most complex, and/or unmet needs in their communities.

Direct versus indirect care

Specialist palliative care is delivered either directly or indirectly.

- **Directly**: to provide direct care to people and/or whānau that are referred for the assessment and management of specific complex need(s). Care is provided in the community or hospital setting, face-to-face and supplemented by telehealth (telephone or virtual consults) as appropriate. Care can be ongoing or episodic (delivered over a defined period until the complex need is addressed and the care of the person and/or their whānau is transferred completely back to their primary palliative care providers). Direct specialist palliative care may need to be accessed around the clock, particularly at the end of life.
- **Indirectly**: to provide general advice, advocacy, support, education and training to other health professionals and volunteers to support the provision of primary palliative care.

Referral criteria

To be referred for adult specialist palliative care services in Aotearoa, the current criteria states people will have:

- An active, progressive and advanced disease/condition.
- A level of need that exceeds the expertise of their usual health care teams(s).
- People will agree to the referral if competent and appropriate to do so (or their whānau/advocate will agree on their behalf).
- If there is uncertainty as to the utility or appropriateness of a referral, a request for verbal advice/guidance should be made.

People receiving active treatment may be referred to specialist services if they meet the criteria.

Where specialist resources are limited, referrals will be prioritised according to need.

Services

The services who can provide this are solely focused on palliative care and have staff with additional expertise. This includes (but isn't limited to) hospices, hospital specialist palliative care teams, and specialist palliative care community teams.

These teams should aim to work collaboratively to serve communities, guided by specialist doctors working together across care settings to provide a seamless and efficient service.

Care settings

People may receive this care (in person or via telehealth) in private homes, aged residential care facilities, rural, secondary and tertiary hospitals, hospice in-patient units, marae or other care settings.

Skill sets

Multidisciplinary specialist teams comprise, at a minimum, specialist-trained doctors, nurses and social support workers (e.g., social workers, Māori support, and counsellors). Access to allied health professionals, cultural support staff (with an understanding of the Māori world view and cultural practices/te ao Māori and tikanga), spiritual care and staff with connection and relationships with local communities is also a requirement.

These skill sets may be accessed through agreements with neighbouring services or regional networks and could be provided via telehealth where appropriate.

Key responsibilities of specialist palliative care services

Holistic, comprehensive assessment

For people with complex symptoms or multidimensional needs, specialist palliative care teams will assess those with complex needs. These services will focus on the holistic assessment of complex physical symptoms, complex whānau dynamics, and psychological and existential distress.

Symptom control

Expert management of complex physical and psychosocial symptoms or complicated comorbidities in all care settings. Admission to inpatient care (e.g., hospice, hospital or ARC) may be required for times when the complexity of care becomes too high to manage in the community.

Psychosocial, spiritual and cultural support

People and whānau will have access to in-depth emotional and spiritual support and bereavement services. Specialist teams will also offer cultural liaison to navigate the challenges of living with life-limiting conditions and end-of-life care, supporting people and their whānau to receive care in culturally meaningful ways.

Access to specialist advice 24/7

Around-the-clock access to specialist advice and support will be provided for both people/whānau and primary palliative care providers managing acute or rapidly escalating concerns. Specialist teams need to be adequately resourced to provide or access crisis management services to ensure people with complex needs receive timely interventions.

Clinical coordination

In addition to the care coordination provided by the person's usual health care team(s), people and whānau receiving direct specialist palliative care often require a designated specialist coordinator to provide a link with, and ensure seamless transitions between, services and settings. Specialist coordinators can facilitate the development of specialist care plans in partnership with the people and whānau. Specialist coordinators will promote timely access to resources and equipment to support care in the home, if required.

Training programs for healthcare professionals

Facilitation of nationally recognised and consistent education for healthcare professionals and carers to enhance skills in palliative care symptom management, care planning and decision-making, and communication.

3.3 Comparisons of primary and specialist palliative care services

Below is a comparison table summarising the key components of primary and specialist palliative care.

Aspect	Primary Palliative Care	Specialist Palliative Care
Service Description	People with non-complex/normal dying and/or stable needs will receive primary palliative care services.	People and whānau with complex symptoms will be referred to specialist palliative care services when their level of need exceeds the expertise of their usual health care team(s).
Services	General practice teams, community/district nursing, aged residential care (ARC), ambulance services, pharmacies, hospital and specialist services, Hauora Māori/iwi services, home and community support services.	Hospices, hospital specialist palliative care teams, specialist palliative care community teams.
Care Settings	Private homes, ARCs, rural, regional and tertiary hospitals, marae, other settings (e.g., prisons).	Private homes, aged residential care facilities, hospitals, hospice in-patient units, marae, other care settings.
Skill Sets	Doctors, nurses, counsellors, social workers, spiritual support workers, allied health professionals, Māori support workers, Kaiāwhina, healthcare assistants/carers, paramedics, other support roles.	Specialist-trained doctors, nurses, social support workers (e.g., social workers, Māori support, counsellors), allied health professionals, cultural support staff.
Referral Criteria for Specialist Care	N/A	Active, progressive, and advanced disease/condition. Needs exceeding primary care expertise. Agreement from the person or their whānau/advocate. Request for verbal advice/guidance if uncertain.
Direct vs. Indirect Specialist Care	N/A	**Directly**: Direct care for complex needs, in-person or via telehealth, ongoing or episodic. **Indirectly**: Advice, advocacy, support, education, and training to primary care providers.
Culturally Responsive Care	Cultural competence and safety training, incorporation of tikanga Māori	Cultural liaison roles to support palliative and end-of-life care with integration of tikanga Māori and community relationships
Holistic Assessment and Care Planning	Initial and ongoing assessments by MDT, individualised care plans	Interdisciplinary assessments, comprehensive care planning, initial and ongoing reviews

Symptom Management	Comprehensive symptom control, regular monitoring, access to specialist care (if required)	Complex symptom control, 24/7 access to care, ongoing follow-up care
Whānau Support and Education	Involvement of whānau, support for caregiving and emotional strategies	Psychological services, grief and bereavement support
Access to Resources and Supports	Aids and equipment, personal care and carer respite, specialist support	Specialist resources, night care, carer education and respite
Interdisciplinary Collaboration	Team-based approach, regular MDT meetings, effective communication	Coordinated specialist care, case management and effective communication
Access to Specialist Support	Referral pathways, 2-way communication channels consultation services, access to palliative care education	Direct specialist care, 24/7 support and advice, education and support to primary services
Advance Care Planning (ACP)	Facilitation of ACP conversations, documentation and accessibility, shared goals of care	Collaborative care planning, comprehensive end-of-life care plan
Psychosocial and Emotional Support	Access to counselling services, including Access and Choice programme	Complex psychosocial and emotional support, structured bereavement services
Community Engagement	Compassionate Community initiatives	Community relationships, engagement in local initiatives
Quality Improvement and Evaluation	Regular feedback mechanisms, outcomes measure, participation in research	Quality audits, participation in research, sector networks and forums
Access to Inpatient Care	As per routine practice	Availability of specialist palliative care input (via in-reach or in-house programmes) across multiple inpatient settings for complex symptom management or end-of-life care.
Whānau-centered Care	Focus on people and whānau needs, communication channels, culturally responsive care plans	In-depth emotional, spiritual, and cultural support, bereavement services, cultural liaison
Holistic Assessment and Planning	Regular assessments of physical, psychological, social, and cultural needs, individualised care plans	Comprehensive assessments of complex symptoms, whānau dynamics, psychological and existential distress
Symptom Management	Management of non-complex symptoms, pain relief, pharmacological and non-pharmacological methods	Expert management of complex symptoms, direct access to inpatient care for high complexity (including inpatient hospice services, ARC and general hospital settings).
Whānau Support and Education	Empowering whānau carers, offering education, information, emotional support, carer respite services	In-depth emotional and spiritual support, structured bereavement services
Referral Pathways to Specialist Care	Clear pathways for timely escalation to specialist services, early intervention for complex needs	Direct specialist care, 24/7 support and advice, crisis management
Access to Care and Support Out of Hours	Plans for timely care out of office hours, acute assessments, collaborations with various services	Around-the-clock access to specialist advice and support, crisis management
Clinical Coordination	Lead clinician for seamless transitions between services, development of individualised care plans	Designated care coordinators, seamless transitions between care settings, individualised care plans
Training Programs for Healthcare Professionals	Basic training in palliative care approaches and symptom management	Facilitation of nationally recognised education, advanced training in symptom management and care planning

4. Collaboration between primary and specialist services

A high degree of collaboration between primary and specialist services is essential to meet the needs of people and ensure transitions between services are experienced as seamless. Peoples' needs often fluctuate, requiring temporary, focused intervention from specialist palliative care teams. After the acute or complex issue has been resolved, care will transition back to the primary palliative care service (eg General Practice team), ensuring efficient use of specialist resources.

Vignette: A Collaborative Approach to Palliative Care

Background:

Mere, a 78-year-old Māori woman living in a rural Canterbury town, has advanced heart failure and chronic kidney disease. She lives alone but has strong ties to her whānau and local marae, and has a caregiver that helps with her morning cares. Her GP, Dr. Patel, has been managing and co-ordinating her care for several years.

General Practice Involvement:

Dr. Patel notices Mere's symptoms are worsening despite changes to her current medications—she's more breathless, fatigued, struggling to take her tablets, and anxious about her future. She initiates a conversation about Mere's goals and preferences, and together they agree to involve specialist palliative care to support symptom management and planning for the future.

Specialist Palliative Care Collaboration:

Dr. Patel contacts the local hospice team, which includes a palliative care nurse, a Māori health navigator, and a palliative care medical specialist. They arrange a joint home visit with Dr. Patel, ensuring cultural safety and continuity of care.

During the visit, the team:

- Reviews Mere's medications, adjusts her diuretics and discusses stronger medications to ease her breathing that don't affect her kidneys.
- Provides emotional support and facilitates a conversation about end-of-life wishes and options to support Mere's desire to remain at home.
- Engages Mere and her whānau in care planning, respecting tikanga and ensuring they know who (and when) to call with questions about Mere's various symptoms and medications, and likely disease progression.

Shared Care:

The hospice nurse stays in contact and visits Mere several times over the next few weeks while she adjusts to the new medications. Mere's whānau call the Hospice Māori health navigator with further questions about how they can support her now and as her condition deteriorates. Dr. Patel remains the lead clinician, and the services keep each other updated.

Outcome:

Mere feels supported by her whānau and GP and her symptoms are better controlled, so the hospice discharges her from their service. She dies peacefully at home several months later surrounded by whānau, under the care of Dr Patel.

Care pathways

Clear referral pathways and 2-way communication are essential for navigation between primary and specialist services. Collaboration is necessary to implement standardised, nationwide pathways and referral guidance that ensure timely specialist care when the needs of people exceed the expertise of primary services.

Episodic specialist involvement

Many people and whānau may not require ongoing specialist input but may benefit from episodic interventions during periods of increased need, including short-term involvement for complex or advanced symptom control (e.g., after a sudden change in condition) or psychological support (e.g., for grief, or to help address specific challenges such as sudden changes in whānau dynamics). The type of episodic intervention required from specialist services may vary and could include indirect advisory care, non-24/7 direct care, or 24/7 direct care.

Flexible care

Services must be flexible between primary and specialist services to meet the complexity and urgency of peoples' needs, with clear referral pathways and communication. After a specialist intervention (e.g., management of an acute symptom flare), the person will often return to the care of their primary team, ensuring that resources are efficiently used.

Support for primary palliative care providers

Specialist teams will be available to provide advice to the person's usual health care team(s), including after hours. This will enable primary palliative care services to manage more complex cases with indirect specialist involvement and reduce unwarranted hospitalisations, interventions and place of care transitions, as well as maintain continuity of care in community settings. This may be a national, regional or locally provided service.

Rapid response from specialist palliative care

It is essential that specialist palliative care services are adequately resourced to respond rapidly to support end-of-life care at home for people who experience sudden decline or unexpected problems that exceed the expertise of the usual health care team(s) before death.

Collaboration agreements

Service sizes and configurations differ across Aotearoa so clear understanding and agreements between services will be essential to clarify the role of each service and how they will work together, especially in crisis care situations and transitions between services and/or care settings.

This will include the development of effective communication and information-sharing protocols between primary and specialist services to ensure rapid updates and timely consultations. This may also include negotiating shared-care agreements between services.

Additionally, all specialist providers will need to work collaboratively within regional networks to ensure all people can access consistent services and achieve equitable care outcomes regardless of their geographic location. This includes ensuring specialist advice to primary palliative care services is consistent regionally and nationally.

Resource-sharing agreements could enable temporary access to specialist personnel or equipment for episodes of care to support services of different sizes and capacities, especially in underserved areas. Shared staffing arrangements can facilitate the deployment of specialists to remote or rural settings, thereby bolstering local care capacity.

These agreements need to support timely and equitable access to the appropriate level of care as needs fluctuate.

Regional palliative care network

Establishing a structure for regional palliative care oversight, including consideration for clinical governance, will help ensure consistent standards while allowing for adaptations to meet local needs, particularly in rural or remote areas. This will enable services of all sizes and capacities to contribute effectively within the regional palliative care network.

5. Partnering with other community services

This proposed national model for integrated adult palliative care introduces a robust framework where flexible collaboration and resource-sharing between primary and specialist palliative care providers is critical to meet the diverse and changeable needs of people and whānau across Aotearoa. The model also acknowledges care in the community requires support from other services, including social care providers. This approach, with seamless transition between primary and specialist levels of care enables services of different sizes and capacities to deliver a full suite of culturally responsive, whānau-centred care to those with life-limiting illnesses regardless of geographic location or other inequities.

Achieving these goals requires engagement, active collaboration and strategic planning across service providers at every level to support seamless care.

Bereavement services

Bereavement services are currently fragmented across providers in Aotearoa and access to bereavement support is variable. Primary and specialist palliative care services will need to engage with existing bereavement services and work collaboratively to improve access to bereavement support.

Navigators/ Kaiāwhina roles

The role of navigators or kaiāwhina is an essential feature of a model of care designed to reach those who are disadvantaged in our health system or have encountered barriers to access in the past. The components of the role are broad, and distinct from care coordinators which are generally clinical and located within a particular service. There are many navigator/kaiāwhina roles already located in community social care settings and engagement and communication from palliative care services is essential. Appendix A has further information about these roles.

Compassionate Communities

Emphasis will be given to a Compassionate Community approach, comprising of formal and informal networks. This includes active participation in initiatives that empower and support whānau, iwi, and communities to care for their own. Community partners, including iwi and whānau groups, would work with specialist services to deliver localised support, further extending the reach of palliative care beyond clinical settings.

Assisted Dying Services

Services will uphold the legal rights of people to access assisted dying services. Quality holistic palliative care is provided to all people and their whānau, regardless of the mode of dying. Services should have clear policies to enable individual choice.

6. Research, Quality Improvement and education

As the Best Practice lead for palliative care in Aotearoa, specialist services will seek to engage in ongoing research and Quality Improvement initiatives to ensure services meet the needs of people and their whānau, meet contractual requirements, and align with international standards.

Primary palliative care services are expected to undertake Quality Improvement initiatives in palliative care within their organisational frameworks and are encouraged to engage in research. Regular feedback from people, whānau, and healthcare providers will inform service delivery improvements.

Outcomes measures

Services are expected to use nationally consistent evidence-based tools to assess people and whānau experiences and outcomes, service efficiency, and satisfaction across the continuum of care. Findings will drive innovation and improve people/whānau-centred care delivery at local, regional and national levels.

Reporting

Services are expected to report NHI level nationally consistent data on both inpatient and community services at a transaction level to support palliative care service planning and funding decisions, as well as service monitoring. This data supports greater understandings of patient utilisation of health services across the system.

Quality standards

The development of national quality standards would ensure that all providers, regardless of size, uphold the same high standard of care. Sharing of training resources between services may be necessary to meet these standards.

Education

Services are expected to ensure their staff receive regular and relevant training and support to deliver high quality care. Services are expected to work collaboratively on the development and delivery of education programmes to improve consistency and efficiencies.

Access to real-time patient information

For people to realise self-determination (mana motuhake) and experience seamless care across services, greater access to real-time patient information is needed by services. This includes the ability for people and services to contribute, and access, information on patient histories, care plans, advance directives, and patient preferences. The development of a national electronic health record would support this and ensure primary, and specialist services can honour peoples' wishes and deliver safe, continuous care across services and care settings.

7. Next steps

Several next steps are recommended to progress this model:

- Te Whatu Ora to seek **public and sector feedback** on the proposed model before finalising this work.
- Te Whatu Ora to develop **Service Specifications** for the roles and responsibilities of specialist palliative care services, including end-of-life care plans for the last weeks to days of life, outcomes measures and reporting requirements.
- Te Whatu Ora to develop **Enhanced Primary and Community Care** funding and reporting arrangements to support primary palliative care.
- Develop local **networks between primary and specialist services** to establish how they will work together, communicate and share resources to ensure all people can access consistent services and achieve better care outcomes over time.
- Specialist palliative care services to develop a national/regional **all-hours phone support** for all primary palliative care healthcare professionals.
- Specialist palliative care services to develop a standardised programme for **whānau/carer education and training**.
- Develop a culturally appropriate **self-management support course** for people and their whānau. These courses may be delivered through a variety of modalities with the added benefit of providing peer support for the participants.

Additional system-wide recommendations include:

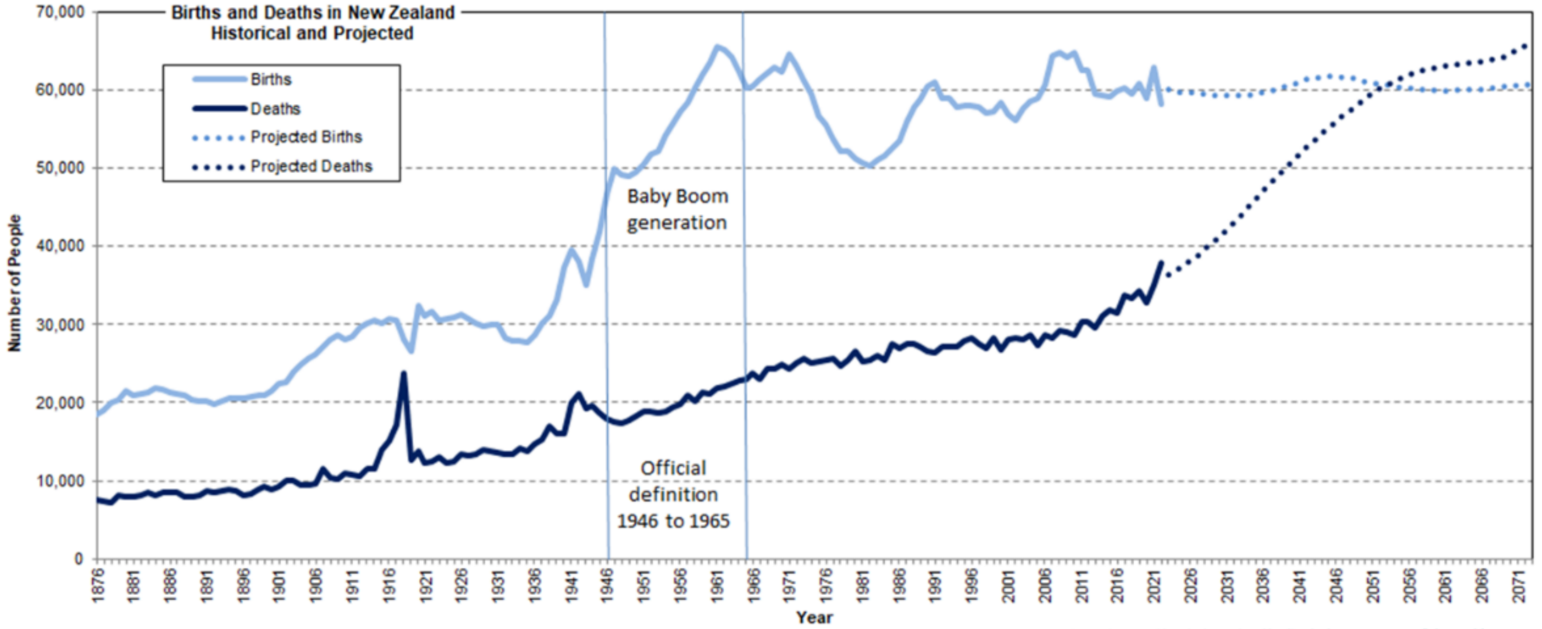
- Develop a **National Quality Standards Framework** and indicators to set nationally consistent care standards with audit processes.
- Develop a **Standards Framework** for the provision of palliative and end-of-life care in aged residential care which is added to contracts and funding for rest home and hospital level care.
- Create a **Shared Digital Health Record** system for real-time access to care plans across all settings.
- Advocate for a **National Bereavement Strategy** to provide consistent follow-up support for bereaved whānau.
- Standardise **HealthPathways** to ensure access to consistent clinical pathway and treatment guidelines nationally.
- Consider **rongoā pathways** to ensure consistent access to rongoā healthcare nationally.

Appendix A: Projection of deaths in Aotearoa New Zealand

Changes in the number of deaths

There has been a steady increase in the number of deaths in Aotearoa over time, with a recent rapid rise in deaths that is projected to continue until the mid-2050s.

Births and Deaths in New Zealand
1876-2022 and projections to 2073

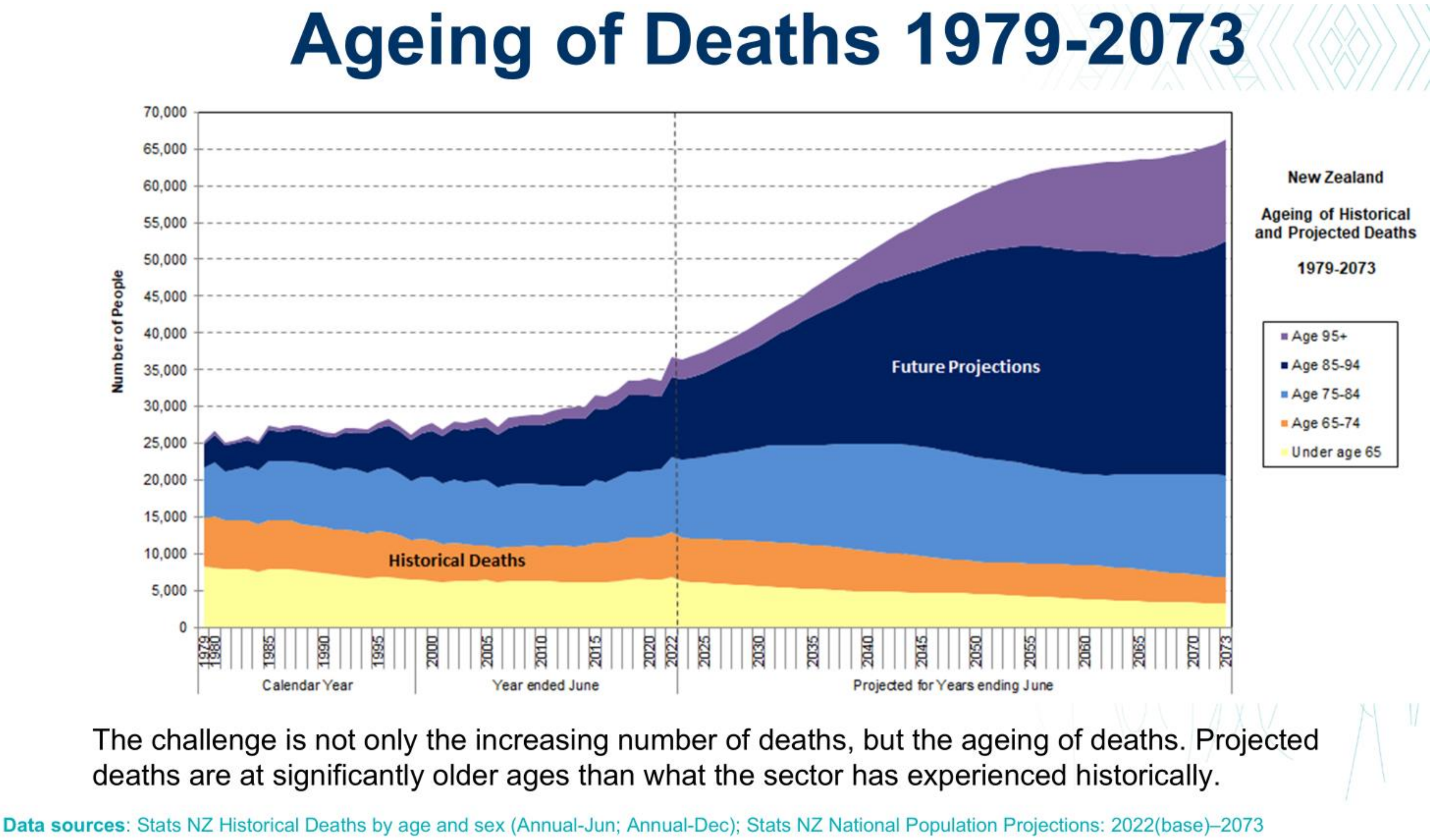


Entries to the world and exits from the world. Deaths have only recently exceeded 30,000 a year. Deaths will catch up to around the 60,000 level each year. Deaths projected to exceed births in 2050s.

Data sources: Stats NZ New Zealand Cohort Life Tables: March 2023 update; Stats NZ National Population Projections: 2022(base)–2073

Changes in the age of people at death

The increases in the number of people dying are most significant in older age groups such as those aged 85-94 years, and over 95 years. The number of deaths of those aged under 75 years is projected to decrease.



Ageing of Deaths 1979-2073

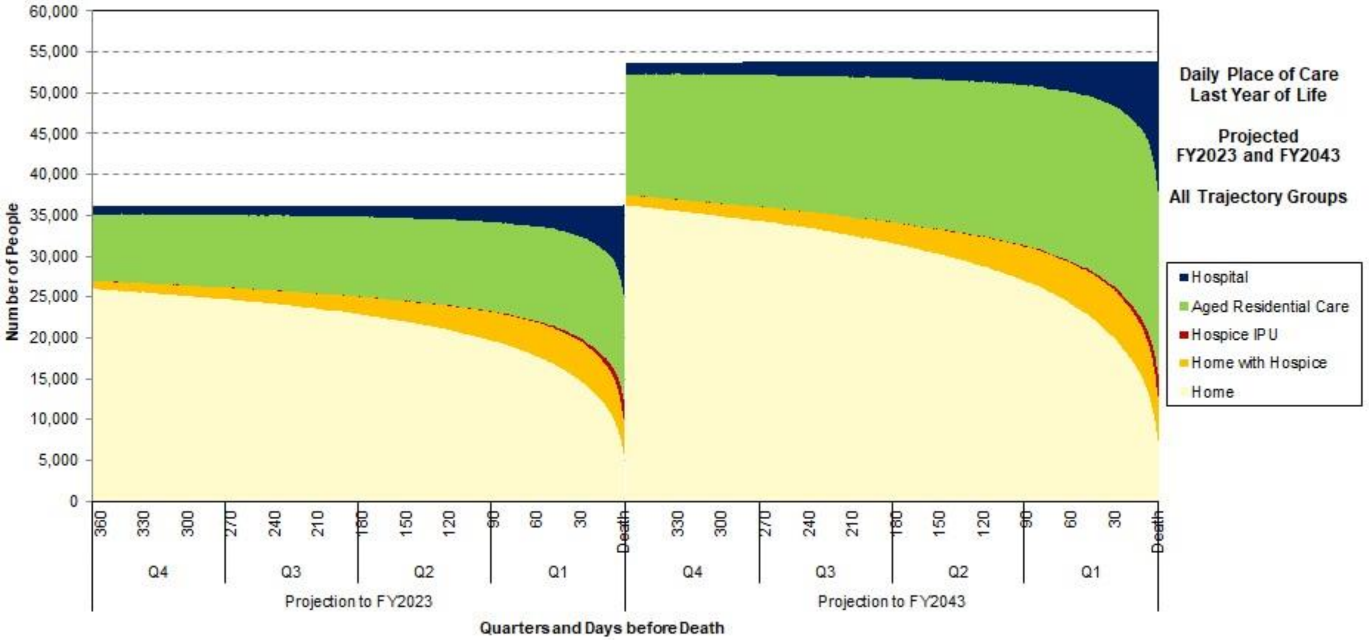
The challenge is not only the increasing number of deaths, but the ageing of deaths. Projected deaths are at significantly older ages than what the sector has experienced historically.

Data sources: Stats NZ Historical Deaths by age and sex (Annual-Jun; Annual-Dec); Stats NZ National Population Projections: 2022(base)–2073

Changes in care settings at the end of life

Projections of deaths over a 20 year period indicate the growing demand for care in ARC and in the community.

All Trajectory Groups, 2023 and 2043



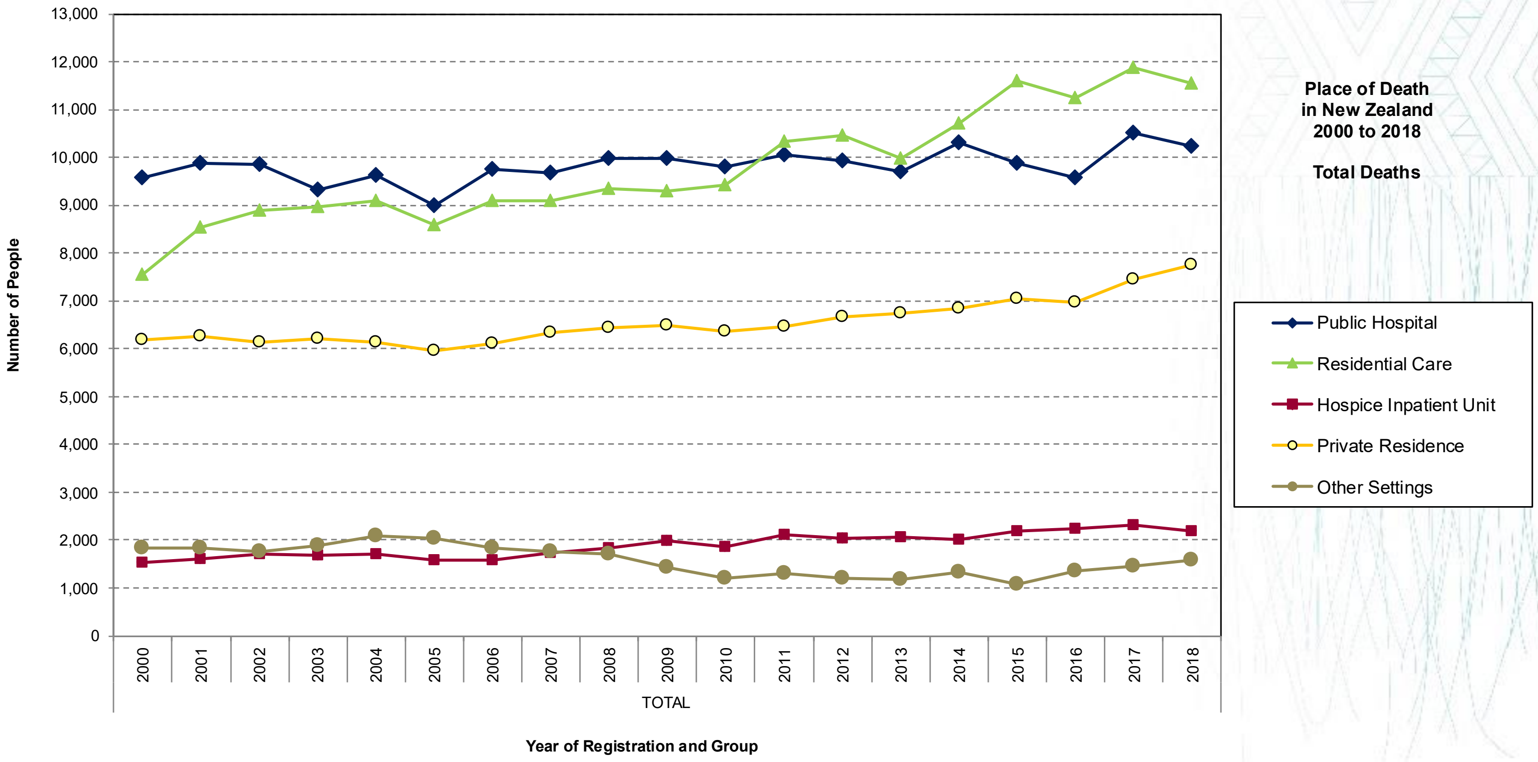
This illustrates the increase in projected total deaths, from 36,300 in 2023 to 53,900 in 2043, an increase of 148%. The ageing of deaths and the increase in size of the Dementia and Chronic Disease groups means days spent in aged residential care are projected to increase 180%.

Data Source: Te Whatu Ora Palliative Care Projection Model vF June 2023 using “Update 2022”

Changes in the place of death

Since 2011, ARC has been the leading place of death for people in Aotearoa and in 2018 accounted for over 40% of deaths. This is closely followed by deaths in hospitals (over 30% of deaths in 2018). These trends are expected to continue.

Place of death 2000 - 2018



- **Heather McLeod 2023. Data source**: MORT Study 2000-2018

Appendix B: Levels of needs

Source: Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand, 2013, pg 8.

3.3 Levels of need

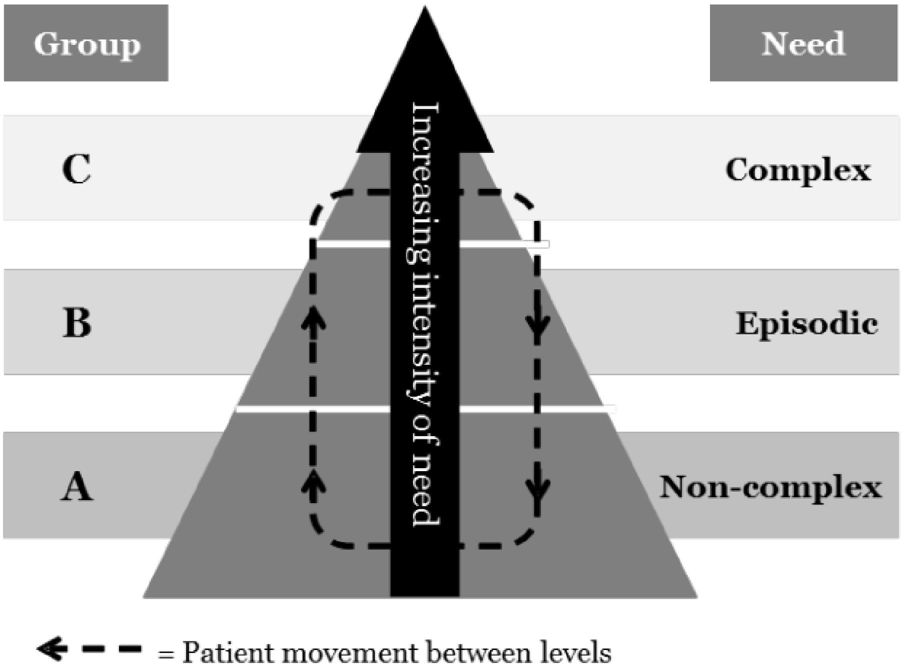
The Framework supports a dynamic approach to specialist palliative care, based on the concept that for many people the need for palliative care can be appropriately met by their existing primary palliative care provider. Research shows that the level of need can be used to classify patients into three groups, as illustrated in Figure 2.

Group A, the largest group, comprises patients whose needs are met by their primary palliative care providers, and these patients do not need to access specialist palliative care.

Patients in Group B require episodic access to specialist services, although these patients continue to have their care managed by their primary palliative care provider in a shared care model.

The smallest group is Group C. The needs of these patients are complex and do not respond to standard palliative care clinical practice guidelines. Group C patients are likely to require ongoing care by specialist services.

Figure 2: Three levels of patient need



Source: Adapted from Palliative Care Australia 2005

Appendix C: Further definitions

People

Service user seeking wellness, consumer seeking wellness, person seeking wellness[10].

Tangata whenua

The term tangata whenua is officially defined in New Zealand legislation and policy as "the iwi or hapū that holds mana whenua (customary authority) over an area." This definition is used in the Resource Management Act 1991 and is reflected in various government documents. More broadly, tangata whenua translates to "people of the land", and refers to Māori as the indigenous people of Aotearoa New Zealand. It can be used to describe Māori in general, or more specifically the local iwi or hapū with ancestral and customary rights to a particular place.

Primary Palliative Care[11]

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 [expertise] 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.

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[10] Te Reo Hāpai. The Language of Enrichment, April 2025. https://www.tereohapai.nz/

[11] https://www.tewhatuora.govt.nz/publications/new-zealand-palliative-care-glossary

Specialist Palliative Care[12]

Specialist palliative care is 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.

Whānau[13]

Whānau is often translated as ‘family’, but its meaning is more complex. [In te ao Māori, whānau can be related or chosen.] It includes physical, emotional and spiritual dimensions and is based on **whakapapa**. Whānau can be multi-layered, flexible and dynamic. Whānau is based on a Māori and a tribal world view. It is through the **whānau** that values, histories and traditions from the ancestors are adapted for the contemporary world.

Rongoā

Rongoā Māori, as defined by the Working Group, is informed by a body of knowledge that has its core the enhancement of Māori wellbeing. Tangata whenua have a strong connection with te ao Māori (the Māori World), their Indigenous cultural values and tikanga (customs). Rongoā Māori (natural Healing approaches) helps to connect Māori to their internal and external worlds. Rongoā encompasses a spiritual healing link that moves beyond physical symptom management (it is more than plant medicines, for example). It is inclusive of people, the whenua (land), soil, and the water flowing through the whenua. Rongoā Māori is a traditional wellness system based on Indigenous cultural concepts and practices, with an emphasis on the spiritual dimension of health. The holistic encompassing nature of rongoā can include a combination of components such as; whānau (family), waiata (song), karakia (prayers, incantations), mirimiri (therapeutic massage), romiromi (deep tissue massage), rākau (plant medicines) and mauri mahi (energy, sound or aural work.)

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[12] https://www.tewhatuora.govt.nz/publications/new-zealand-palliative-care-glossary

[13] Tai Walker, 'Whānau – Māori and family', Te Ara - the Encyclopaedia of New Zealand, http://www.TeAra.govt.nz/en/whanau-maori-and-family/print

Navigators/ Kaiāwhina

The role of navigators or kaiāwhina is an essential feature of a model of care designed to reach those who have traditionally been disadvantaged in our health system. The components of the role are broad, and distinct from a care coordinator role which tends to be more clinical and ensconced within a particular service.

Te Pae Waenga / the Draft New Zealand Health Plan 2024-2027 mention kaiāwhina within the living well section of the plan. "The focus of Living Well is to prevent, diagnose them early, reduce the risk of complication, and provide people with the resources to manage their own condition…This includes a range of health professionals like GPs, pharmacists, physiotherapists, social workers and paramedics, and other health workers like kaiāwhina, health coaches and navigators". This work fits well with the Te Pae Waenga definition of quality which describes quality as "ensuring the health care and services delivered in New Zealand are safe, easy to navigate, understandable and welcoming to users, and are continuously improving"[14]. This definition of quality goes well beyond clinical quality and speaks to this navigator role.

The primary aim of the role is to build trust; to provide whānau driven, culturally appropriate care that is mana enhancing (strengthening of a person's inherent dignity, authority, and spiritual essence) for the recipient and supports them to develop the relationships and skills so they can access the care that they require.

The role is diverse and may include some aspects of coordination particularly in terms of removing physical barriers to attend appointments such as cost, transport, and child minding, as well as social barriers of competing needs, interpreting across not only language barriers but also health literacy barriers.

The role includes case management, patient education, social work, and advocacy, which may involve overcoming disparity even prior to engagement with health services[15].

While a navigator may share some duties with a care coordinator the latter is usually a more clinical role. "Care coordination is the deliberate organisation of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organising care involves the marshalling of personnel and other resources needed to carry out all required patient care activities and is often managed by the exchange of information among participants responsible for different aspects of care"[16].

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[14] https://www.tewhatuora.govt.nz/corporate-information/planning-and-performance/health-workforce/health-workforce-plan-2024/profession-specific-analysis/kaiawhina-and-care-roles

[15] https://tatou.health.govt.nz/achieving-pae-ora-healthy-future/navigators

[16] https://www.ahrq.gov/ncepcr/care/coordination/atlas/chapter2.html

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