

Palliative Care Action Plan

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Contents

Executive summary	v
Introduction	1
Scope of this plan	1
What will the future look like?	2
Why develop an action plan?	3
Working with the sector to develop the action plan	3
Does the action plan differ from the recent Review?	4
A person-centred model of adult palliative care	4
What is this action plan addressing?	8
What is happening internationally?	9
Features and focus of the action plan	10
Preparing for the future	10
Building on feedback and consultation	10
Building on other strategies	11
Looking across different timeframes	12
Addressing the five priority areas	14
Priority 1: Respond to the voices of people with palliative care needs and their families and whānau	14
Priority 1 actions	15
Priority area 2: Ensure strong strategic connections	17
Priority 2 actions	18
Priority 3: Improve quality in all settings	20
Priority 3 actions	20
Priority 4: Increase emphasis on primary palliative care	22
Priority 4 actions	23
Priority 5: Grow capability of communities and informal carers	25
Priority 5 actions	25
References	28
Glossary	29
Appendix 1: Resources to support implementation of this action plan	30
Appendix 2: Relevant policies and plans	31

Executive summary

New Zealand's population is ageing and an increasing number of people are living longer. All sectors recognise the imperative to prepare for these trends. In the health sector, our system needs to change to meet the growing demand for palliative care, which is projected to increase by 51 percent over the next 22 years. So it is in everyone's interests to plan now for a refreshed direction for palliative care to meet increasing demands on (and expectations of) palliative care services and service providers.

The vision for New Zealand is that people live well and die well. People need to have confidence that at the end of their life they and their loved ones, if needed, will have access to high-quality palliative care that is consistent across all settings. This will be provided by a palliative care system that is culturally competent so people can stay connected with their cultural values throughout their end of life journey. While this plan is inclusive of all cultures and belief systems, it recognises the unique place tangata whenua play in design of future palliative care services in New Zealand.

Palliative care in New Zealand engages almost the entire health system. It connects with other government agencies and is a focus for spiritual and cultural groups. Whānau, and family carers, volunteers and other community members are increasingly recognised as critical members of the care team, who also need support.

Throughout the engagement for the *Review of Adult Palliative Care Services in New Zealand* in 2016 (the Review), feedback from the sector showed that some areas have excellent palliative care practice and many people die well in New Zealand. However, it also indicated that good practice is variable and not everyone can access high-quality care (Ministry of Health 2017).

The Review identifies challenges that will make it difficult to meet future palliative care demands. It recommends a refreshed strategic direction for palliative care to meet those demands.

The Review sets out five priority areas. These areas are developed in response to evidence about what matters to people at the end of their life. They are also in line with the New Zealand Health Strategy's five strategic themes and New Zealand Health Strategy Roadmap of Actions 2016.

Review actions set a future focus for palliative care that draws on collective work by the Ministry of Health and the health sector. These actions provide the foundations for a multidisciplinary approach through good primary palliative care in primary care, community, hospital and aged residential care settings.

An action plan is needed to provide a structured approach to inclusive and collaborative strategic planning and to improve the way that each of the Review's five priority areas work in practice.

Introduction

This action plan supports the findings, priorities and actions of the *Review of Adult Palliative Care Services in New Zealand* (Ministry of Health 2017). Please read it along with the Review.

The Review identifies challenges that will make it difficult to meet future palliative care demands. It recommends a refreshed strategic direction for palliative care to meet those demands. The Review outlines actions under five priority areas to achieve the refreshed direction. These priorities are to:

1. respond to the voices of people with palliative care needs and their families, whānau
2. ensure strong strategic connections
3. improve quality across all settings
4. increase emphasis on primary palliative care
5. grow capability of communities and informal carers.

These priorities are in line with the New Zealand Health Strategy and Roadmap of Actions 2016 and Healthy Ageing Strategy vision and priorities for action. They show how strategic thinking about, planning for and implementing palliative care can contribute to and be supported by other Ministry of Health work programmes.

This plan signals how people nearing the end of their life and their significant others will get respectful care, as well as the support they need to be actively involved in their own care.

Feedback from engagement and consultation has shown some areas in New Zealand have excellent practice in palliative care. This action plan aims to build on that good work to make sure that compassionate care is available to all.

Scope of this plan

The scope of the review was limited to adult palliative care. It also had to work within current fiscal constraints.

These same limits apply particularly to the short-term initiatives outlined in this action plan. Medium- and longer-term impacts and scope will be discussed with Government and are likely to be further defined in mid to late 2018.

Definitions of palliative care and the palliative care approach

These definitions clarify key terms in the action plan. For explanations of more terms related to palliative care, see the New Zealand Palliative Care Glossary (Ministry of Health 2015a).

Palliative care is care for people of all ages with a life-limiting or life-threatening condition. It aims to:

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

Patients transition to palliative care at the time they are told they have a life-limiting condition. They receive palliative care according to their individual need. It may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when people are getting treatments aimed at increasing their quantity of life.

Important features of palliative care are that it should be:

- available wherever the person lives
- provided by all health care professionals, supported where necessary by specialist palliative care services
- provided in a way that meets the unique needs of individuals from particular communities or groups. This includes but is not limited to Māori, children and young people, immigrants, those with intellectual disability, refugees, prisoners, the homeless and those in isolated communities (Palliative Care Subcommittee NZ Cancer Treatment Working Party 2007)¹.

Palliative care approach

In its origins and early years of development, palliative care largely focused on meeting the needs of people with cancer, often in a hospice setting. Now, both internationally and in New Zealand, it is shifting to recognise the benefits of palliative care for people diagnosed with any life-limiting illness, not just cancer.

A palliative care approach is an approach to care that embraces the definition of palliative care. In this approach all service providers working with the person and their family:

- have a positive and open attitude toward death and dying
- respect the wishes of the person in relation to their treatment and care.

What will the future look like?

In the future, people who need palliative care will live well and die well. They will have confidence that at the end of their life they and their loved ones, if needed, will have access to high-quality palliative care that is consistent across all settings

People will have the support they need for a respectful end of life, so that they are cared for physically, culturally and spiritually, and die, in an environment that feels safe and comfortable.

1. <https://www.health.govt.nz/system/files/documents/publications/nz-palliative-care-definition-oct07.pdf>

The New Zealand health workforce has the skills to deliver primary palliative care throughout the country. Specialists provide support and advice as required.

High-quality palliative care is, at its heart, people-centred and responsive. Health professionals have the skills to use a patient-centred model of adult palliative care with the focus on primary palliative care, with support, where necessary, from specialist palliative care services. Patients, family and, whānau will feel confident they can access any physical, cultural, spiritual and bereavement supports they need. They receive enough information to make choices if they wish to and where possible about the care they receive.

Why develop an action plan?

To achieve the above vision, the Review recommends actions under five priority areas aimed at managing future demand and achieving the overarching goals in adult palliative care. An action plan is needed to provide a structured approach to improving how each of the Review's five priority areas works in practice.

It provides a bridge between strategic thinking and implementation.

An action plan also helps to coordinate the developments in one area of the health system and to integrate them with key strategies, policies and frameworks that make system-wide changes.

This action plan details how to achieve outcomes at different levels and within organisations across the system. It sets out best-practice change management that involves improving the system in ongoing spirals.

An action plan supports stakeholders to focus their priorities, planning and resourcing for change.

Working with the sector to develop the action plan

The action plan rests on advice and feedback from consumers and the health sector, including health and aged care providers. The national Palliative Care Advisory Panel provided advice on the plan's development.

This action plan now centralises a compassionate and integrated model of care. This will require many sector groups, organisations and health professionals to work together in the best interests of the person nearing the end of life.

Achieving the action plan will be sector led

A refreshed strategic direction for palliative care must include all key stakeholders. They are the ones to make change within their organisations. Together, they shape the future and the quality of palliative care across all settings. Health care providers already have collaborations, partnerships and alliances.

This action plan sets 2017–2018 as the timeframe over which key stakeholders will discuss and agree on sector leadership models for immediate and longer-term actions.

Key stakeholders include but are not limited to service users/consumers, district health boards, regional alliances, hospitals, hospices, aged residential care facilities, doctors, nurses, pharmacists, allied health, community and home health.

The action plan has Ministry support

The Ministry of Health will lead the effort to achieve the vision of the action plan by:

- acting as steward of New Zealand health, and having connections across government and with non-governmental organisations
- backing the action plan with the collective power of its overarching strategic direction, programmes and quality standards, many of which are relevant to palliative care
- developing this action plan, which provides the sector with a framework to focus its discussions, agree on priorities and frame its roadmap
- providing internal leadership and resource to coordinate and facilitate palliative care hui for sector-wide information and strategic discussions about actions, agreed ways of working and leadership models.

Does the action plan differ from the recent Review?

The action plan differs from the Review in some key ways. In particular, the action plan:

- focuses on the short term (2017–2018) while including enough medium-term and long-term thinking to give confidence in the direction of early actions
- highlights that change, as promoted in the New Zealand Health Strategy, is system-wide and takes time. For palliative care it sets an expectation that the sector will have ongoing conversations across all levels to achieve change
- introduces a person-centred model of adult palliative care as a result of engagement and consultation with experts and consumers
- Priorities are re-ordered to reflect a person centred approach.

A person-centred model of adult palliative care

The proposed person-centred model of care is a key tool in successfully achieving the vision for adult palliative care. It clarifies roles, responsibilities, possible new ways of working and how parts of the sector can interact with others more seamlessly.

As a result of strong consumer feedback, this proposed model moves the focus from the Resource and Capability framework to the wider view of holistic care and support that people want at the end of their lives.

The proposed model promotes exploring new ways that specific services can contribute to the multidisciplinary palliative care team. For example, how Age Residential Care fits into the model, pharmacists might visit people at home for medicine management; district nurses could be trained in high-level palliative care; and initiatives might find ways of better using ambulance officers and paramedics to support palliative care, particularly in remote areas.

Figure 1 summarises the important features of this model. Figure 2 identifies the ways for making it happen.

Figure 1: Proposed person-centred model of adult palliative care

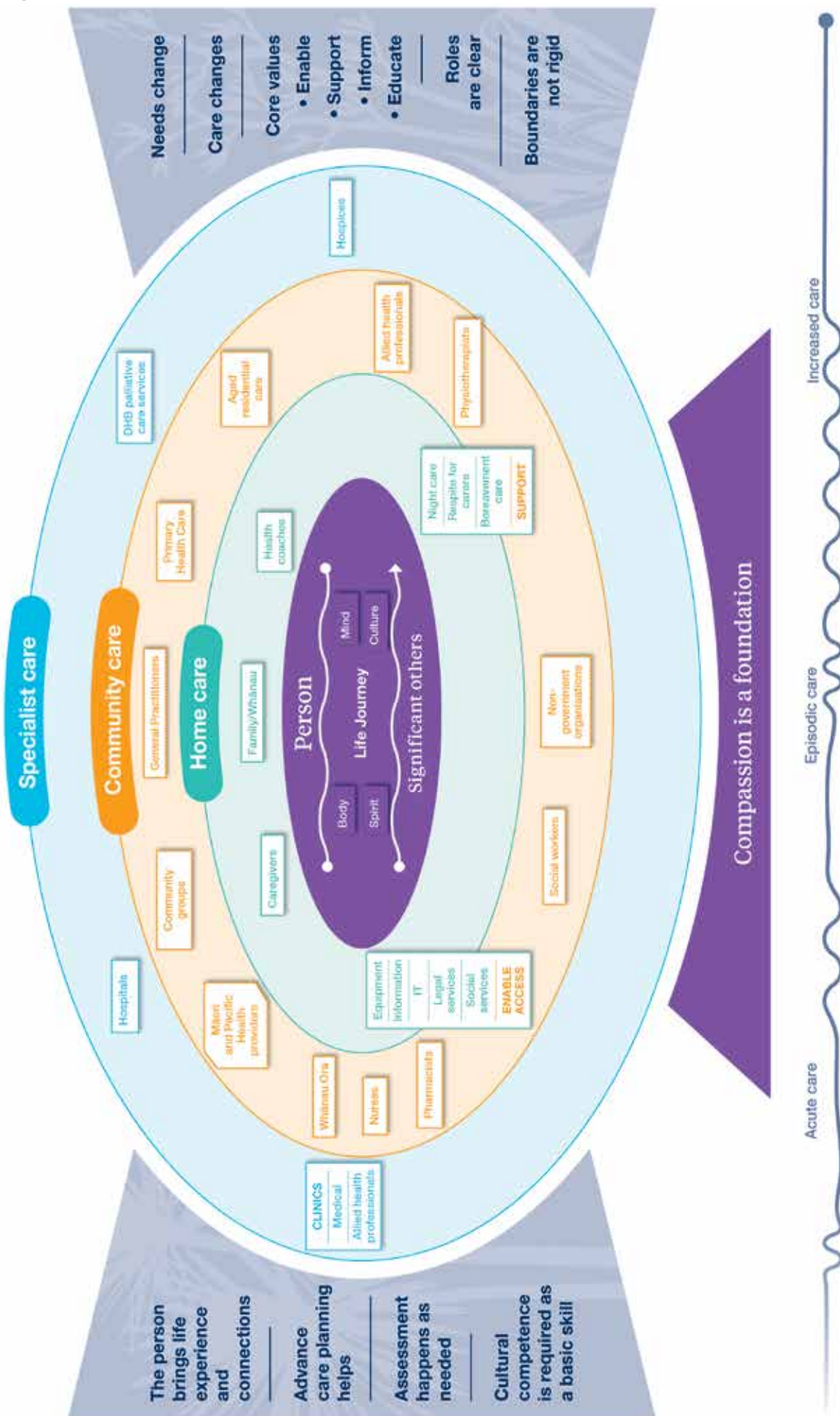
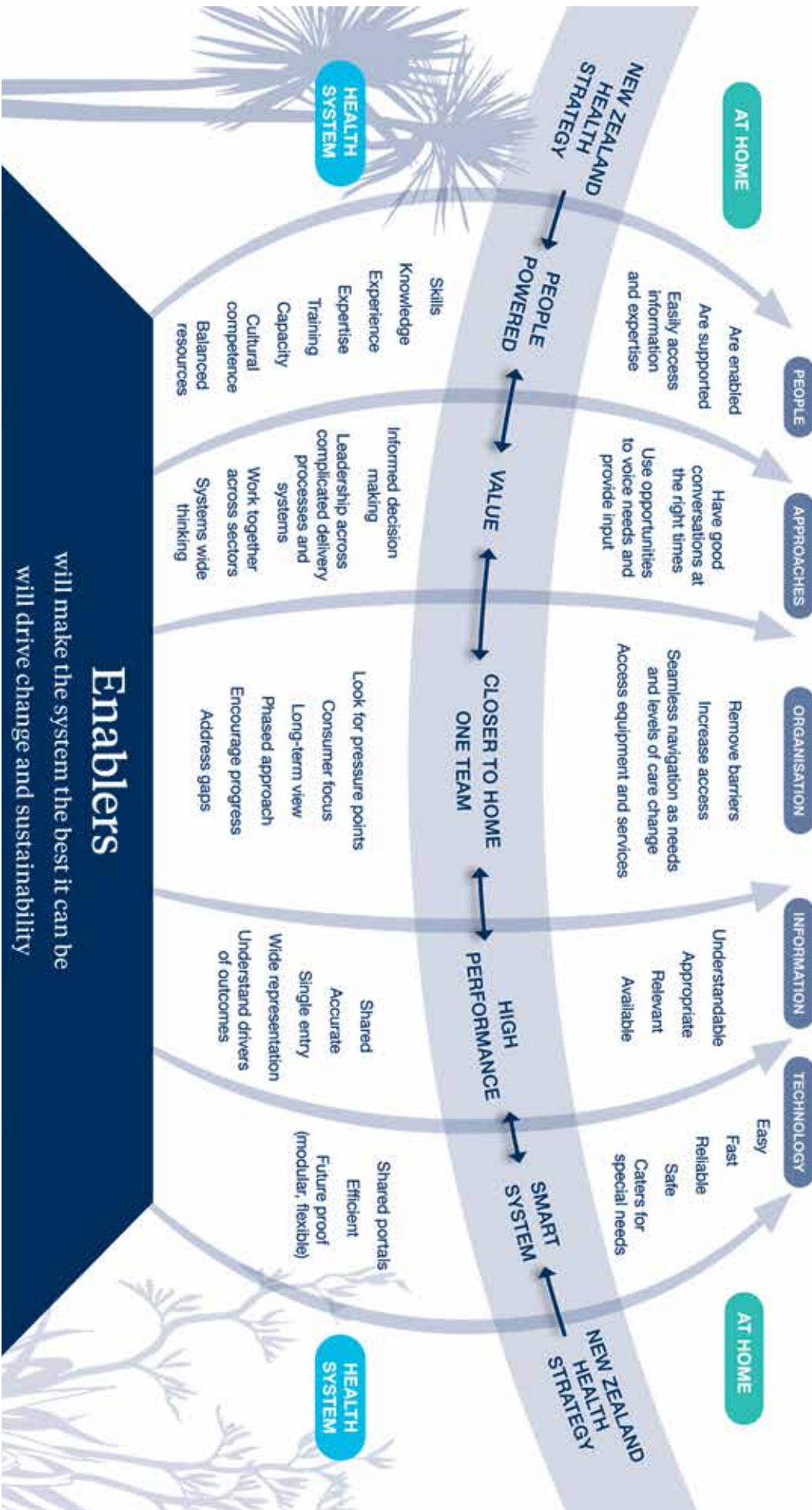


Figure 2: Drivers of the person-centred model of care



Putting the person-centred model into practice

Figure 2 highlights ways of helping put the proposed person-centred model of adult palliative care into practice.

Leadership

- When leaders collaborate, their united purpose is a powerful driver for sustainable system-wide change.
- The basis of this action plan is that sector leaders together explore current work, new thinking, shared purpose, and agreed ways of working and partnership synergies. The Palliative Care Advisory Panel provides a sector overview for quality and consistency.
- The health partnership and alliance models operating in New Zealand provide useful learning for sector leaders as they plan for future palliative care volumes and demands.

Training

- Agreeing on minimum levels of training in palliative care for most health professionals immediately increases the size of the workforce available to manage the projected increase in need for palliative care.
- The system becomes more flexible when most health professionals have core training in palliative care and have the support of a sufficient and sustainable specialist workforce.
- Professionals within the sector have already developed palliative care training modules that could be adapted to create quality minimum standards of knowledge and skills in palliative care across the sector.

Guidance and tools

- Palliative care is provided in almost all settings where health care is provided, including acute hospitals, general practices, aged residential and community care services, and generalist community services. National guidance supports staff across health organisations in New Zealand to understand the essential components of high-quality palliative care. Tools provide a quality framework for decisions and actions across all settings.
- New Zealand's *Te Ara Whakapiri: Principles and guidance for the last days of life* (Ministry of Health 2015b) outlines the essential components and considerations required to promote high-quality care at the very end of life for all adults in New Zealand.

Information and other technologies

- The Ministry is actively encouraging investment in models of care and services that meet individuals' needs efficiently. Increasingly those models of care rely on well-designed information technology that integrates services across health care settings.
- Consumers and their families want to be able to access the information they need, typically online. Centralising information, advice and resources will help people navigate the system.
- Although sharing patient information records has challenges, it is a helpful way of achieving an integrated response to end-of-life care and palliative care.

Communication

- Communication sets the vision for change and keeps people united.
- Clear, consistent communications are essential for people to confidently progress initiatives and work across organisations and agencies.

What is this action plan addressing?

Variability and inequity

Many people die well in New Zealand. However, palliative care practice is variable and not everyone can access high-quality, culturally responsive care when and where they need it.

Integrating services to respond to changing needs

On their life journey, people's health needs change and they have to be able to find their way through the different parts of the health system that can meet those needs.

The health system can be difficult for a patient who is getting services from a number of different providers that are not sharing their health information and, sometimes, are working in siloes, isolated from each other. Patients and their family and whānau are often the intermediaries between providers, communicating the health information they need. This can be challenging for them.

The action plan provides opportunities to look at how providers can better support family members who are helping a patient navigate the health system.

Ageing population

New Zealand's population is ageing and an increasing number of people are living longer. The health system needs to change to meet the growing demand for palliative care services.

A whole-of-person approach

Palliative care has a wider reach than many people realise. The whole-of-person approach is about physical as well as spiritual health and meeting cultural needs. It involves almost all of the health system and connects across government agencies.

Although most people would prefer to die at home, hospitals, aged residential care and hospices are likely to remain places for death and dying for many. For this reason, the sector needs to agree about an approach to palliative care that supports excellent care for dying patients and their family and, whānau in all settings.

Diverse needs

New Zealand has an increasingly diverse population. In 2015 Auckland's population had over 200 ethnicities; 50 percent of the population was Māori, Asian and Pacific peoples; and 44 per cent were not born in New Zealand.

Māori have previously had variable experiences of palliative care. They seek a whānau-oriented approach to care.

Knowledge is limited about the needs and preferences for palliative care among Pacific and Asian populations.

This action plan indicates ways to provide services that are culturally appropriate.

What is happening internationally?

Like New Zealand, other countries are planning ways to meet the needs of an ageing population that is living longer and likely to need palliative care.

Internationally, recent strategic thinking and approaches to palliative care have been moving towards patient-centred holistic care, in which communities, family, whānau and patients themselves – where possible and if they wish to – are empowered to be members of the care team along with primary palliative care providers.

Other common themes in current international strategies are:

- responding to people's voices
- developing community capability
- supporting home and community care
- engaged, informed individuals and carers
- partnerships between health care and social care professionals
- palliative care education and training
- holistic palliative care
- coordinated, high-quality care
- talking about death and dying
- economic evaluation of palliative care models
- developing shared patient-centred outcome measures across all settings.

For more information, see:

- Ontario, Canada: Ministry of Health and Long-Term Care. 2015. *Patients First. A Roadmap to Strengthen Home and Community Support*
- Scotland: Scottish Government. 2015. *Strategic Framework for Action on Palliative and End of Life Care*
- United Kingdom: NHS England. 2014. *Actions for End of Life Care: 2014–2016*.

Features and focus of the action plan

This action plan focuses initially on delivering outcomes for 2017–2018. It also presents a broader view of the medium- to long-term future as demands for adult palliative care increase because of the growing and ageing population.

Preparing for the future

Moving from strategy to action in complex environments, across many levels of organisation, is a challenging and long-term endeavour. The value of following a clear and inclusive process cannot be underestimated as a way of taking everyone along on the journey.

This suggested sequence of steps focuses effort on where it is most needed. Taking each step will involve ongoing consultation with all key stakeholders where appropriate.

Define a care or service model.

1. Define key options and pathways for implementing the model.
2. Define financial models and options within current funding.
3. Work up indicative estimates of resource and capability required for selected options.
4. Work up a detailed cost and benefit analysis of each preferred option or pathway.
5. Propose ways of measuring outcomes for preferred options.

This staged approach:

- gives the palliative care sector and Government confidence that agencies are working together in the best possible way to improve palliative care in New Zealand
- increases understanding of the context for medium- and long-term development
- engages a wide range of individuals and organisations and gains their support for possible future solutions
- uses public funds more effectively and responsibly.

Building on feedback and consultation

This plan has been developed through consulting with consumers and the health sector, as well as with feedback from Ministry of Health groups. Feedback from 100–150 consumers, health and aged care providers is now part of the action plan. The national Palliative Care Advisory Panel has also given advice throughout the plan's development.

Building on other strategies

Table 1 sets out the key strategies and plans that this action plan aligns with, including the New Zealand Health Strategy.

Table 1: Strategies and plans that this action plan aligns with

Strategies		Life stage(s)	Responsibility
2016	New Zealand Health Strategy	Whole of life	Ministry of Health
2016	Healthy Ageing Strategy	Whole of life	Ministry of Health
2014	He Korowai Oranga: Māori Health Strategy	Whole of life	Ministry of Health
2014–2018	'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018	Whole of life	Ministry of Health
2014–18	The New Zealand Carers' Strategy Action Plan	Whole of life	MSD
2001	Primary Health Care Strategy	Whole of life	Ministry of Health
2001	Palliative Care Strategy	End of life	Ministry of Health
2001 2014	Positive Ageing Strategy Positive Ageing Strategy Report	Mid–late in life	Office for Senior Citizens, Ministry of Social Development
Action plans			
2016	Pharmacy Action Plan 2016-2020	Whole of life	Ministry of Health
2015	Te Ara Whakapiri	Last days of life	Ministry of Health
2014	Health and Disability Kaiāwahina Workforce Action Plan	Whole of life	Ministry of Health
Other			
2014	Equity of Health Care for Māori: A framework	Whole of life	Ministry of Health
2014	National Professional Development Framework Palliative Care Nursing Practice	Whole of life	Ministry of Health
2012	Palliative Care Resource and Capability Framework	End of life	Ministry of Health
2012	Measuring What Matters: Palliative care	End of life	Ministry of Health

Social investment approach

The New Zealand Health Strategy is, in essence, a social investment strategy. It is concerned with focusing analysis, outcomes and service design to understand the needs of people who require public health services and the impact those services have on people's lives.

Within palliative care, the focus is on implementing the New Zealand Health Strategy as a social investment approach to health. Figure 3 gives an overview of the central elements of this kind of approach.

Figure 3: Central elements of social investment approaches



Use what is already happening

In the short term this plan draws on work organisations associated with palliative care are already doing. It can reuse or repurpose much of this work. For example, *A National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand* (Ministry of Health 2014) was adapted from an earlier publication by the National Cancer Nursing Education Project.

Looking across different timeframes

This action plan has both an immediate and longer-term focus.

2017–2018

The focus for 2017–2018 is to engage the sector in conversations about what can immediately be actioned while improving understanding of needs, reach and options. These two years set a pathway for future direction, actions and leadership.

This action plan recommends that the palliative care sector aims to keep what is relevant and renew direction where required. It provides important bridging steps to move the sector towards acting as one team, working smarter and practising the principles of good palliative care where pragmatically and immediately possible.

Medium- to long-term

Being ready for and sustainable over the medium to long term gives the action plan a sense of direction.

To achieve this, the action plan sets out sector leadership workshops that the Ministry of Health will resource and facilitate with the aim of building cross-sector palliative care leadership for cross-sector work and initiatives. This work might include cross-sector modelling for future planning.

Palliative care leaders include representatives of key stakeholders. For example, they will include doctors, palliative care specialist nurses, district health boards, regional alliances, hospices, aged residential care facilities, pharmacists, allied health care, community health care, volunteers, service users and people in the community.

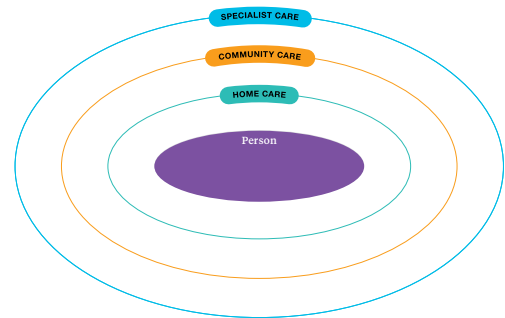
Progress reports will inform the Minister of Health about developments in the priority areas. They will also note other actions that may arise throughout the implementation period as part of an inclusive approach with wide engagement or to keep pace with developments and thinking in the field.

Addressing the five priority areas

Priority 1: Respond to the voices of people with palliative care needs and their families and whānau

Why is this important?

Palliative care has an important role in supporting family, and whānau during what can be a profound and/or challenging time. People want carers to hear them and meet their needs in a respectful way. They want to know they can access physical, cultural, spiritual and psychological support, as well as bereavement support if they need it. Little nationwide evidence has been systematically gathered to understand the experience of the patient at the end of life and their family and whānau.



What will success look like?

There is a systematic approach to gathering evidence of patients and family / whānau experience. People say their carers are considering and meeting their needs and preferences. Families and whānau get the guidance and support they need. Providers listen, respond and learn.

People say communication is clear. They and their family are informed about proposed approaches to treatment and care and are involved in making decisions about their care.

What are the opportunities for change?

Using a person-centred model is an opportunity to implement a system to hear people's voices and realise the benefits of the New Zealand Health Strategy, by meeting need in a way that is culturally appropriate.

How will this be achieved?

Gather insights from consumers. Plan response in consultation with the Health Consumer Advisory Service New Zealand (HCASNZ).

Priority 1 actions

Short-term actions, 2017–2018: Initiate and design

Action	Who	When
<p>Develop a framework for a national survey of patients, family, and whānau from different ethnic and socioeconomic groups about their experiences of adult palliative care. Its aim is to understand what is working well, needs of particular groups and opportunities to improve support, including for iwi and hapū. Build on learnings from piloting of the VOICES survey.*</p> <p>As part of the survey, look at equity of access to respite and bereavement care for informal carers across the country – identify and document gaps.</p>	Te Arai Palliative Care and End of Life Research Group, University of Auckland, Ministry of Health	2017
Explore options and co-design appropriate channels and methods for ongoing communication and engagement with patients, family and whānau including those in hard-to-reach groups.#	Ministry of Health HCASNZ	2017
Continue to produce relevant information and resources to support quality improvement for patients and their family and, whānau.	Sector leaders Ministry of Health	2017–18
Reflect consumer voices in intervention logic by reviewing and revising earlier Palliative Care Council documents.	Ministry of Health HCASNZ	2017
Investigate opportunities for assessing the reach and impact of advance care planning in palliative care.+	Ministry of Health	2018

* The views of informal carers' evaluation of services (VOICES): Toward an adaptation for the New Zealand bicultural context
R Frey, L Williams, G Trussardi, S Black, J Robinson, T Moeke-Maxwell

See Appendix Resources that could support implementation of this action plan

+ The Health Quality and safety Commission is managing an advance care planning (ACP) programme and training for 2016/2017 year.

- Evaluation of ACP is being carried out in 2016/17.
- The future form of ACP training will be suggested as part of the five-year plan developed from evaluation findings.

Medium-term actions, 2019–2024: Implement

- Follow up on the National Survey 1 findings of patients, families and whānau about their experiences of palliative care, using an approach of understanding consumer needs, subject to discussion with health stakeholders and funders.
 - Identify gaps to address and options and further actions to take that will help improve quality in palliative care supports for patients and their family and, whānau.
-
- Subject to discussions with stakeholders and funders, propose culturally appropriate responses to meet the needs of different cultural, ethnic (particularly Māori) and socioeconomic groups through current or planned workstreams.
 - Implement the approved responses.
-
- Consumers continue to contribute to the design of relevant resources and information.
-
- Subject to discussion with health stakeholders and funders, a National Survey 2 to report new findings and any changes in findings from National Survey 1, and makes recommendations.

Long-term actions, 2025–2030: Embed

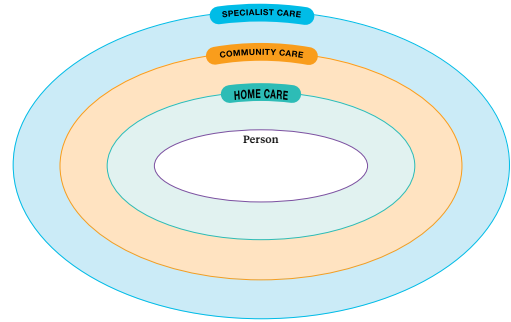
- Follow up National Survey 2 of patients, families and whānau about experiences of palliative care, subject to discussion and planning after reporting to the Minister of Health.
 - Refine continuous improvement in embedding good practice.
-

Priority area 2: Ensure strong strategic connections

Why is this important?

All groups involved in palliative care are part of wider networks and strategically connected in various ways.

- Palliative care is connected to the Ministry of Health's key strategies, policies and frameworks.
- It touches most parts of the health sector.
- Palliative care provides more than a way of relieving pain and managing other symptoms. It helps address the emotional, spiritual and cultural needs of patients, often through partnership with other government agencies.
- Existing alliances and partnerships across the health sector and government agencies support developments and initiatives that benefit everyone.



A key tool for change is to engage with communities, non-regulated staff, health professionals, managers/funders, and district health boards, the Ministry of Health, consumer groups, non-governmental organisations and aged care providers so they can learn about and agree to a shared vision.

All groups involved with palliative care benefit from strategic connections and leadership to improve and/or expand the quality and scope of their palliative care services.

What does success look like?

Health strategies are aligned with each other. People say care is coordinated.

All palliative care organisations and agencies experience the positive outcomes of clear leadership, strong partnerships and connected ways of working.

The sector and consumers are contributing to the development of key health strategies. In the Ministry of Health's stewardship role, Ministry groups collaborate to ensure the developments in palliative care inform and contribute to implementation of wider health strategies.

Key sector leaders have collectively engaged, led and contributed to palliative care and addressed issues. As a result, providers are cooperating and coordinating their services and are providing high-quality care at the end of life.

Strong networks exist between palliative care specialists and primary palliative care teams alongside the person being cared for, their family, whānau, and friends, and their community. Everyone works together as one team to support people to die well and to support family and whānau during the illness and into bereavement.

What are the opportunities for change?

The New Zealand Health Strategy provides a unified focus on a number of the challenges facing palliative care. Collaboration across programmes, such as the Pharmacy Action Plan, can shift thinking and make better use of resources.

For everyone connected with palliative care, collaboration among leaders across sectors and in the allied health sector can drive change.

How will this be achieved?

Collaborate with health and community representatives through leadership workshops that the Ministry of Health facilitates with the aim of building cross-sector and community palliative care leadership for cross-sector work and initiatives. This work might include cross-sector modelling for future planning.

Develop a Stakeholder Engagement Plan to engage consumers, providers and government sector partners who are leaders at national, regional, local and community group levels.

Priority 2 actions

Short-term actions, 2017–2018: Initiate and design

Action	Who	When
Support collaboration, synergies and operating initiatives by producing a diagram that shows how relevant health and public sector strategies align with and relate to each other.	Ministry of Health	2017–2018
Develop a Stakeholder Engagement Plan to engage consumers, providers and government sector partners who are leaders at national, regional, local and community group levels. The Ministry will develop this plan collaboratively with sector leaders and key representatives to outline an approach, timetable and who will lead actions.	Ministry of Health to coordinate Co-design with sector	2017–2018
Consult with the allied health sector and pharmacists to identify opportunities for better use of allied health force skills and expertise. Agree on next steps. Set up a focus group to lead the work.	Ministry of Health Sector leaders	2017–2018
Work with agencies, including regional health alliances, district health boards, hospitals, aged residential care, hospices, primary care, pharmacists and allied health services to understand impacts of population trends and palliative care scenarios on: <ul style="list-style-type: none"> • palliative care services • operating models • commissioning models • Treasury’s long-term fiscal modelling. Recommend one to three operating (and commissioning) models to investigate further.	Ministry of Health	2017–2018
Put in place plans that support palliative care by sector leaders advocating for: <ul style="list-style-type: none"> • shared electronic patient health records and patient portals • clinicians, hospitals, aged residential care and people developing advanced care plans and advance directives. 	Ministry of Health Palliative Care Advisory Panel Sector leaders National ACP Cooperative Round Table	2017–2018
Encourage all levels of palliative care to communicate planned messages using similar language.	Sector leaders Consumer representatives	2018
Following the Kaiāwhina Workforce Action Plan, support the growth and development of the non-regulated workforce.	Health Workforce New Zealand Careerforce	2017–2018

Medium-term actions, 2019–2024: Implement

- Learn from earlier engagements with strategic partners by reviewing and refreshing the diagram that shows how relevant health and public sector strategies align with and relate to each other. Run 2019 engagements as planned.
 - To ensure key messages are consistent, coherent and communicated effectively, check the effectiveness of engagement/communication with key strategic stakeholders and agree on improvements as required.
 - Assess uptake of allied health expertise to support palliative care across primary care, aged residential care, community and tertiary care settings.
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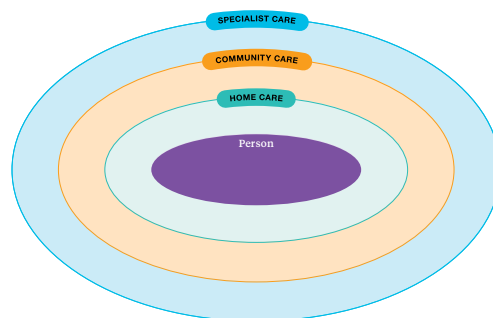
Long-term actions, 2025–2030: Embed

- Stocktake. Identify gaps in strategic direction and plan further actions.
-

Priority 3: Improve quality in all settings

Why is this important?

People want to be confident that high-quality palliative care is available when they come to the end of their life. Agreed standards for quality palliative care build workforce capability and high-performing teams.



What does success look like?

People are confident they can readily access high-quality palliative care for themselves or loved ones. There is national agreement on what high-quality palliative care is. All areas of the health system use quality standards of adult palliative care. Nationally we target care better throughout life, including at end of life and for bereavement.

What are the opportunities for change?

Having a core set of performance outcomes helps to improve the quality of service across all groups involved in adult palliative care.

As Groeneveld et al (2017) observe, ‘Clinical teams and palliative care providers share the responsibility in leading improvements and reducing variation in care by defining good practice and measuring their activity, costs and outcomes.’ This action plan provides a way for this to happen by setting up the structure and impetus for cross-sector clinical leadership and consumer engagement.

Words that describe outcomes can be confusing. The Ministry of Health develops population-based targets and outcomes. The palliative care sector is considering the best approach for New Zealand to reflect and report on clinical palliative care outcomes.

How will this be achieved?

The Ministry of Health will facilitate a health and community leaders’ forum and consultation with interest groups. Small working groups will lead the next steps.

Priority 3 actions

Short-term actions, 2017–2018: Initiate and design

Action	Who	When
The sector agrees on a population outcomes framework. Agree on population-level quality indicators for palliative care. Include access and equity in the indicators.	Sector leaders Ministry of Health	2017
The sector investigates clinical outcome measures to assure quality of care for individuals receiving palliative care. (This work is under way with a discussion paper developed in February 2017.)	Hospice NZ and sector	2017
Agree on an independent evaluation framework for the outcomes of the innovation funding proposals to improve the quality of palliative care in aged residential care, primary care and community settings.*	Ministry of Health	2017

Action	Who	When
Implement Healthy Ageing Strategy action: 'Support the implementation of <i>Te Ara Whakapiri: Principles and guidance for the last days of life</i> '.	End-of-life care providers	2017
Use research and evaluation results to review quality dimensions for palliative care in aged residential care facilities. Development of older people's palliative care clinical care guides for residential aged care, in collaboration with Te Arai Palliative Care and End of Life Research Group, UoA, aged care sector, and Ministry of Health.	Te Arai Palliative Care and End of Life Research Group, University of Auckland, aged care sector, and Ministry of Health.	2017–2018
Collaborate in developing an outcomes framework.	Cross-sector	2018
Agree on minimum service expectations for palliative and end-of-life care for use in all settings (for example, aged residential care, primary care, hospital and hospice). Use a range of channels to communicate minimum expectations for palliative care across all care providers.	Sector leaders	2018

* Innovation funding proposals: Ministry funded and hospice managed national process supporting the development and evaluation of high quality business plans to improve the quality of, and access to, community palliative care services, specifically through aged residential care, primary care and/or other community services.

Medium-term actions, 2019–2024: Implement

- Test and trial minimum service expectations as they are implemented and monitor them across all settings.
- Assess nationwide results of the evaluation of innovation funding outcomes. Make recommendations for next steps.
- Test and trial guidelines for palliative care in aged residential care facilities as they are implemented.
- Agree on indicators for population-level outcomes for palliative care. Co-design methods for measurement.
- Trial and test new training approaches that have resulted from best practice. Define ways to scale-up successful approaches.
- Prioritise and select key issues to focus on for next steps and use a continuous improvement cycle.

Long-term actions, 2025–2030: Embed

- Assess the impact of minimum service expectations across all settings and target special strategies.

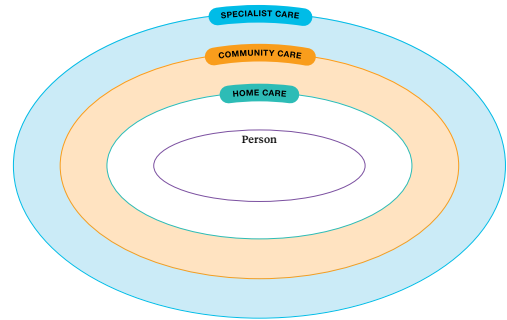
Priority 4: Increase emphasis on primary palliative care

Why is this important?

All health care professionals who are caring for a person with a life-limiting illness provide primary palliative care. They gain support where necessary from specialist palliative care services.

Primary palliative care providers, and their relationships with specialist palliative care providers, are key to responding effectively to the projected increase in palliative care need.

With a stronger focus on primary palliative care and on the knowledge and skills of the primary palliative care workforce, the sector can build or develop quality standards of palliative care and encourage health care professionals across all settings to follow them.



What does success look like?

Roles, boundaries and levels of palliative care are clarified with input from key personnel. The sector has agreed on and implemented guidelines for moving between different levels of palliative care.

Providers work together to integrate services. People understand the different levels and options in palliative care and who best offers what service.

All members of the health team are able to provide, or know how patients, family and whānau can access, the cultural, spiritual and psychological supports they need.

What are the opportunities for change?

Strengthening all health care professionals' palliative care capability increases the number and diversity of health professionals nationally available to manage the higher demand for palliative care in the future. It increases workforce flexibility to provide responsive, targeted care to meet diverse needs.

Health care professionals have an important role in helping people to talk about death and dying and prepare better. Primary care professionals can support people to make informed choices by having conversations with them about advance care plans and giving information about the integrated system of supports available for patients, their family and whānau.

The stronger focus on primary palliative care is also an opportunity to improve access to high-quality education and training in palliative care.

How will this be achieved?

Consult with key stakeholders and facilitate working groups.

Priority 4 actions

Short-term actions, 2017–2018: Initiate and design

Action	Who	When
<p>Advocate for using advanced care planning and <i>Te Ara Whakapiri</i> in primary care hospitals, aged residential care and hospices as way of improving the quality primary palliative care, building on shared care planning and patient portals.</p>	<p>Royal New Zealand College of General Practitioners, aged residential care facilities, hospitals</p> <p>Allied health professionals</p> <p>Health sector leaders, Public health organisations</p>	2017
<p>Agree on the points in the person-centred model of adult palliative care that are priorities for defining more precisely. For example, clarify the:</p> <ul style="list-style-type: none"> • boundaries between specialist palliative care and primary palliative care • role of specialist palliative care • roles and best use of expertise of allied health professionals in supporting palliative care • roles and best use of <i>kaiāwhina</i>, pharmacists (including clinical pharmacists and pharmacist prescribers), allied health, advanced nursing professionals and specialist palliative care nurses. 	<p>Palliative Care Advisory Panel</p> <p>Sector leaders</p> <p>Ministry of Health</p>	2017–2018
<p>Work with key stakeholders to identify impacts on the workforce of the person-centred model for primary palliative care.</p>	<p>General practitioners, primary care sector, Health Workforce New Zealand, Careerforce, district health boards, hospitals, aged residential care providers, specialist clinicians</p> <p>Public health organisations</p>	2017–2018
<p>Support understanding of palliative care across primary palliative care services.</p> <ul style="list-style-type: none"> • Encourage and promote conversations with the sector about minimum expected knowledge and skills related to primary palliative care. • Support work to modify undergraduate education and training to provide the minimum knowledge and skills related to primary palliative care. 	<p>Sector leaders</p>	2017–2018
<p>Define success and identify needs and gaps related to ‘Measuring what matters’ and the ‘Resource and capability framework’. Propose actions to implement across primary palliative care.</p>	<p>Sector leaders</p> <p>Ministry of Health</p>	2017–2018

Medium-term actions, 2019–2025: Implement

- Ensure palliative care knowledge and skills are a part of undergraduate and postgraduate education and training in medicine, nursing, allied health, health care assistants CAs and other professions as appropriate.
 - Revise national referral guidance for specialist palliative care to better support sector understanding of the interface between specialist and primary palliative care.
 - Roll out new palliative care guidance and training programmes.
 - Scope centralised online medical information and training resources.
 - Scope evaluation processes for training initiatives in palliative care and advance care planning across the country.
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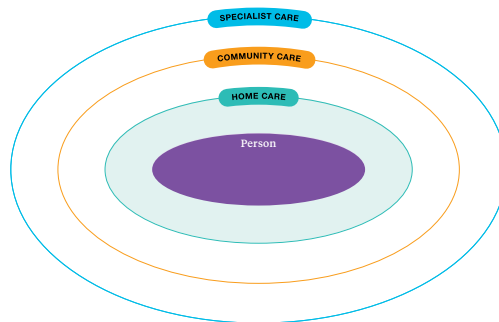
Long-term actions, 2025–2030: Embed

- Assess the impact of minimum service expectations and target primary palliative care strategies.
-

Priority 5: Grow capability of communities and informal carers

Why is this important?

With a person-centred approach, people who wish to can stay at home for as long as possible. Informal carers, communities and networks are a large part of the wider palliative care team. They are important for the growth and development of palliative care and for consultation and collaboration. Through this the health sector learns from what informal carers and communities already do well. The importance of their role has implications for providing resource and education to support minimum expectations of care in the home.



Families, whānau and caregivers need to feel confident that the system recognises diverse needs and supports their contribution in meeting these needs.

What does success look like?

Families, whānau, interest groups and communities promote understanding of and compassionate responses to death and dying.

Individuals, their family, whānau and other informal carers say they get the guidance and support they need and in a culturally appropriate manner. They feel part of a team.

What are the opportunities for change?

Family, and whānau and other informal carers are key supports for a person who is dying. When they get better support, they can contribute to the wider team to support the person physically, culturally and spiritually. Cross-government collaboration can explore ways to support family carers.

How will this be achieved?

Collaborate with consumer and community groups and training providers.

Priority 5 actions

Short-term actions, 2017–2018: Initiate and design

Action	Who	When
Define carer groups (home and community support, volunteers, communities, unpaid (family) carers, paid carers).	Ministry of Health Health Workforce New Zealand	2017
Conduct a stocktake of options for technologies that support people, families and whānau in their homes and give them easy access to specialised support and advice.	Consumer panel Ministry of Health	2017

Action	Who	When
Continue the Ministry's working relationship across government agencies in issues of carer support, for example the New Zealand Carers' Strategy (2008) and the New Zealand Carers' Strategy Action Plan for 2014 to 2018.	Ministry of Social Development, Accident Compensation Corporation, Ministry of Health, Ministry of Business and Innovation	2017–2018
Assess needs and gaps in workforce development for carers, kaiāwhina and the home and community support workforce.	Ministry of Health Palliative Care Advisory Panel Sector leaders	2017–2018
Develop a strategy that addresses the communication needs of diverse carers, including by providing information about respite, guidance and training in line with the Government's Carers' Strategy Action Plan 2014 to 2018.	Representation from consumer panel, volunteers Sector leaders, Ministry of Health, key agencies	2017–2018
Assess the contribution and needs of volunteers in palliative care across all sectors.	Sector leaders and consumer panel	2018

Medium-term actions, 2019–2024: Implement

- Roll out new training and development programmes for carers, kaiāwhina and the home and community support workforce.
- Introduce supportive technologies for the informal carers, communities, networks and home carers where possible.
- Share effective models of community collaboration with palliative care and support services.
- Gather evidence about the growth of capability in community and carers sector. Identify gaps and next steps.

Long-term actions, 2025–2030: Embed

- Assess the impact of training and development and target community development strategies.

In a nutshell: what changes will we see as a result of this action plan?

- New Zealanders are discussing death and dying more widely as a part of life's continuum. People and their families and whānau feel confident they can make well-informed decisions about their end-of-life circumstances where they want to and can readily access the supports they need.
- Inequitable access is challenged and addressed.
- All service providers working with the person and their family have a positive and open attitude toward death and dying, and respect the wishes of the person in relation to their treatment and care.
- A larger pool of high-quality palliative care supports meets palliative care needs in flexible ways.
- The many levels of organisations involved in palliative care contribute seamlessly to quality standards. People feel confident they will have the support they need to die well and to meet their bereavement needs.



References

Groeneveld EI, Cassel JB, Bausewein C, et al. 2017. Funding models in palliative care: lessons from international experience. *Palliative Medicine* 1–10.

Ministry of Health. 2014. *A National Professional Development Framework for Palliative Care Nursing Practice in Aotearoa New Zealand*. Wellington: Ministry of Health.

Ministry of Health. 2015a. *New Zealand Palliative Care Glossary*. Wellington: Ministry of Health.

Ministry of Health. 2015b. *Te Ara Whakapiri Principles and guidance for the last days of life*. Wellington: Ministry of Health.

Ministry of Health. 2016. *Review of Adult Palliative Care Services in New Zealand*. Wellington: Ministry of Health.

Glossary

New Zealand Palliative Care Glossary (December 2015)

Many of the terms defined in the palliative care glossary have held various meanings, resulting in inconsistent use and confusion. This glossary aims to initiate a common understanding of terms used in palliative care in New Zealand.

The Palliative Care Council of New Zealand, Hospice New Zealand and the Ministry of Health have all been involved in its development.

www.health.govt.nz/publication/new-zealand-palliative-care-glossary

Ministry outcomes framework

The Ministry outcomes framework for palliative care services is based on **population outcomes for DHB's publicly funded palliative care services**. The outcomes framework clarifies the desired outcomes for a specific population, such as all people and their whanau who are eligible for funded palliative care services living in Nelson Marlborough DHB region, for example. This palliative care framework contributes to the National expectations for the prevention and management of long term conditions and its line of sight population outcomes framework

It recognises that this population will be served by many different agencies and programmes **that contribute to the desired outcomes for the specific population**.

The performance outcomes framework includes indicators and measures for services so the Ministry know that, collectively, their services are supporting the population to achieve the desired outcome and can be used to benchmark similar services to support improvement activities.

Example of a palliative sector clinical outcomes framework: Australia's Palliative Care Outcomes Collaboration (PCOC)

PCOC is a national programme that uses standardised clinical assessment tools to measure and benchmark patient outcomes in palliative care. Participation in PCOC is voluntary and can help palliative care service providers to improve practice and meet the Palliative Care Australia Standards for Providing Quality Palliative Care for all Australians. This is achieved through the PCOC data set, a multi-purpose framework designed to:

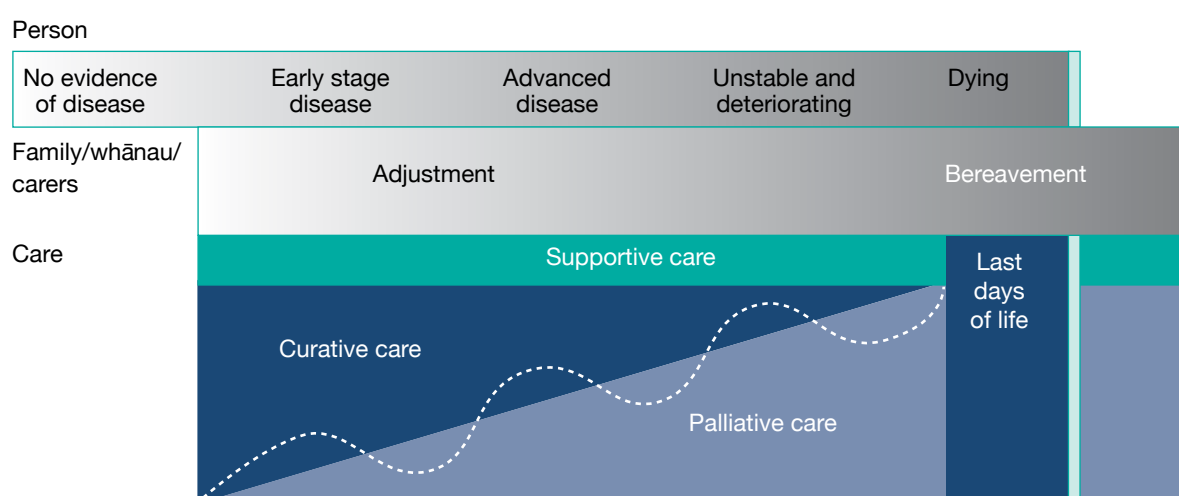
- provide clinicians with an approach to systematically assess individual patient experiences
- define a common clinical language to streamline communication between palliative care providers
- facilitate the routine collection of national palliative care data to drive quality improvement through reporting and benchmarking.

The PCOC data set includes the following clinical assessment tools: Palliative Care Phase, Palliative Care Problem Severity Score (PCPSS), Symptom Assessment Scale (SAS), Australia-modified Karnofsky Performance Status (AKPS) scale and Resource Utilisation Groups – Activities of Daily Living (RUG-ADL).

Appendix 1: Resources to support implementation of this action plan

Adjustment, support and palliative care for adults

Figure from New Zealand Palliative Care Glossary (December 2015)



Māori health literacy and communication in palliative care: Kaumātua-led models

www.health.govt.nz/system/files/documents/publications/maori-health-literacy-communication-in-palliative-care-kaumatua-led-models-aug14.pdf

Medical Council resource booklet 'Best Health Outcomes for Pacific people:

www.mcnz.org.nz/assets/News-and-Publications/Statements/Best-health-outcomes-for-Pacific-Peoples.pdf

Pasifika bereavement research eg,

www.hrc.govt.nz/sites/default/files/23807%20HRC%20Pacific%20News%201213_online_rev1.pdf

Palliative care research considering Pacific peoples

www.unitec.ac.nz/advance/index.php/how-our-culture-affects-our-death

The National Institute for Care and Excellence (NICE) in the UK: Care of dying adults in the last days of life. www.nice.org.uk/guidance/qs144

This guidance calls for health care professionals to ask adults in the final days of life about their religious or spiritual beliefs. Newly developed by NICE in response to estimates that three out of four deaths are anticipated by medical staff, it provides guidance to help health care professionals identify patients who are nearing death in order to allow the patient and those close to them prepare accordingly.

Appendix 2: Relevant policies and plans

Minister of Health. *The New Zealand Health Strategy and Roadmap*. (2016)
www.health.govt.nz/publication/new-zealand-health-strategy-2016

Ministry of Health. *Healthy Ageing Strategy* (2016)
www.health.govt.nz/publication/healthy-ageing-strategy

Ministry of Health. *The Guide to He Korowai Oranga Māori Health Strategy* (Updated 2014)
www.health.govt.nz/publication/guide-he-korowai-oranga-maori-health-strategy

Ministry of Social Development. *Positive Ageing Strategy Report* (2014)
www.msdl.govt.nz/documents/what-we-can-do/seniorcitizens/positive-ageing/msd-17470-2014-ageing-strategy-report-final.pdf

Ministry of Health. *Equity of Health Care for Māori: A framework* (2014)
www.health.govt.nz/publication/equity-health-care-maori-framework

Ministry of Health. *'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2014–2018*
www.health.govt.nz/system/files/documents/publications/ala-moui-pathways-to-pacific-health-and-wellbeing-2014-2018-jun14-v2.docx

Ministry of Social Development. *The New Zealand Carers' Strategy Action Plan for 2014 to 2018*
www.msdl.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/

Health Workforce New Zealand (HWNZ) and Careerforce. *Kaiāwahina Action Plan*
www.workforceinaction.org.nz/

Ministry of Health. *Te Ara Whakapiri*
www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life

Ministry of Health. *Pharmacy Action Plan*
www.health.govt.nz/publication/pharmacy-action-plan-2016-2020

