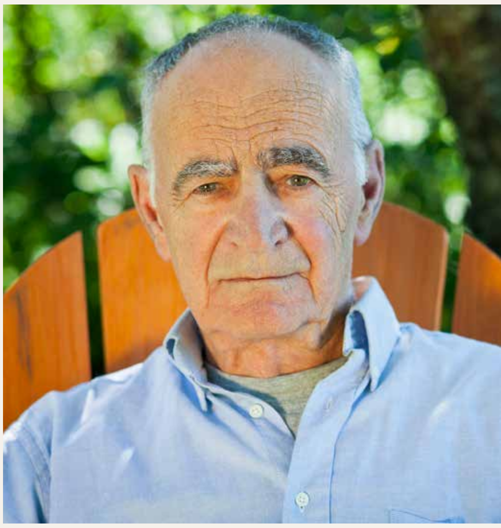








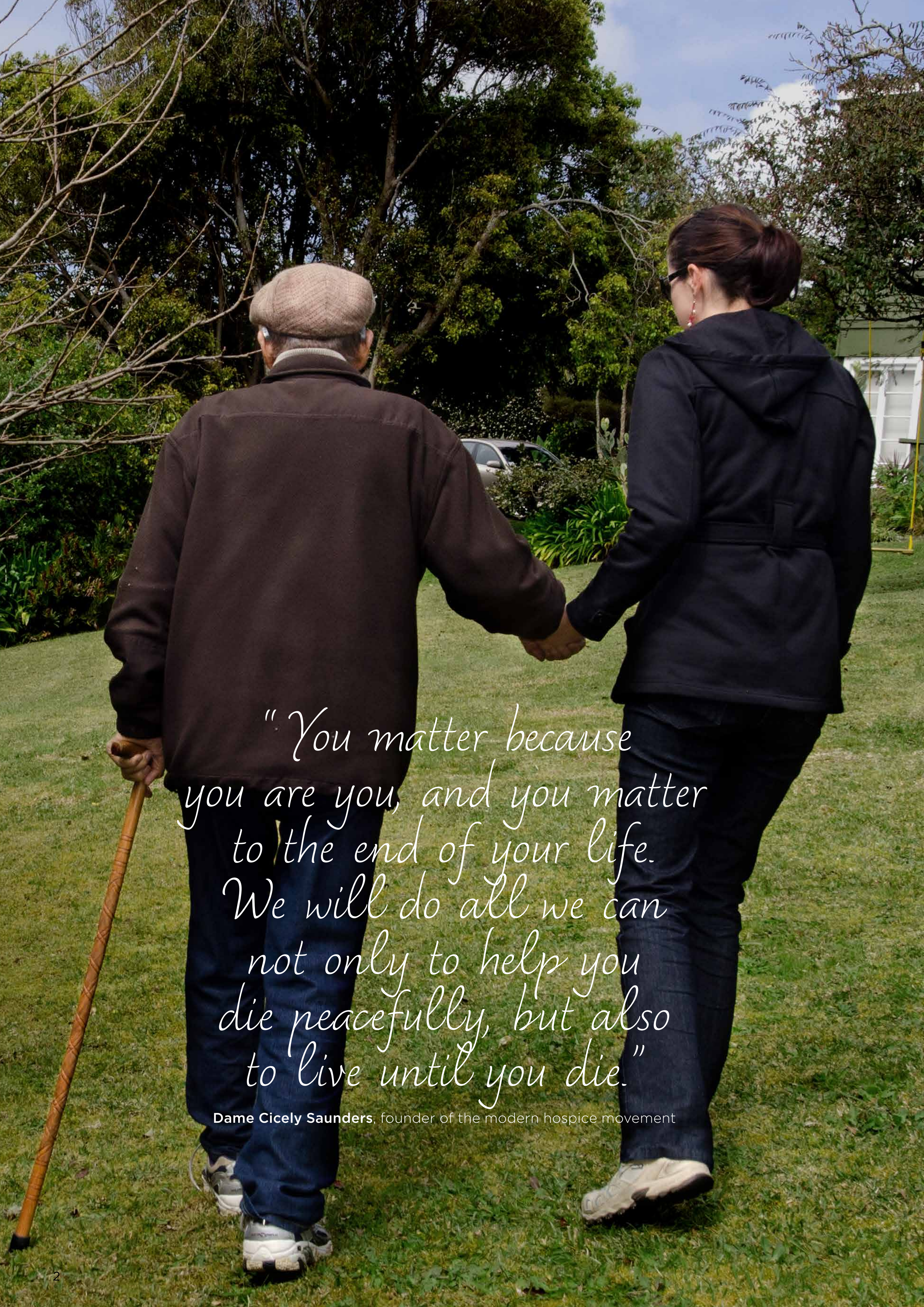
Living Every Moment
hospice
New Zealand

Ngā paerewa pairuri tāngata

Standards for Palliative Care 2019

Ihirangi

Contents



> "You matter because
> you are you, and you matter
> to the end of your life.
> We will do all we can
> not only to help you
> die peacefully, but also
> to live until you die."

Dame Cicely Saunders, founder of the modern hospice movement

He kupu takamua

Foreword

E ngā mana, e ngā reo, e ngā karangatanga maha, nei rā ngā whakamānawa nui ki a koutou katoa. Ki te hunga mate kua hoki ki te kōpunitanga o ngā wairua, moe mai, moe mai rā. Ki a tātou katoa ngā kanohi ora o rātou mā – tēnā koutou, tēnā koutou, tēnā hoki tātou katoa.

Nau mai, haere atu ēnei kupu aroha, ēnei kupu whakataurangi, hei pairuri i te tangata puta noa i te motu, tihe mauri ora!

The vision of Hospice New Zealand is that everyone with a life-limiting condition, their family and whānau, have access to the best possible palliative care.

The Hospice New Zealand Standards for Palliative Care have been developed to support all hospice services to deliver consistent and best quality palliative and end-of-life care for people regardless of locality and diagnosis. We acknowledge that each person's experience is our collective responsibility and priority. The primary focus is on providing care for the person who is dying, whilst also supporting their family and whānau both before and after their loved one has died.

This is the fourth edition of Hospice New Zealand Standards. The latest edition has been developed in consultation with all members of Hospice New Zealand. They provide a suite of nine standards that articulate and set out expectation, whilst providing guidance with interpretation and application for all hospices.

The Standards address and reflect recent changes within palliative care and hospice and focus on the future. The process has been supported by a governance group, working party, reference group and specialist advisors.

Our vision is that the Standards will support hospices to develop their services and maintain a continuous quality improvement approach to their service planning process. Whilst they have been written for hospices in the first instance, our long-term vision is that other providers of palliative care across many settings will adopt, or use, the Standards to enhance and support their care and services.

Hospice New Zealand would like to thank all those that contributed to the development of these Standards for their commitment, time and expertise. We believe they will make a big difference to the people who need our support and services.

He aha te mea nui o te ao, he tangata, he tangata, he tangata

What is most important in this world, it is people, it is people, it is people

Mary Schumacher
Chief Executive
Hospice NZ

Ngā kupu whakamihi

Acknowledgements

Hospice New Zealand thank and acknowledge the hospices, health partners and individuals for their guidance and contribution to the development of the Hospice New Zealand Standards for Palliative Care.

The Ministry of Health for their ongoing support and funding for the development of the Hospice New Zealand Standards for Palliative Care.

Palliative Care Australia for their support and for allowing us to use the National Palliative Care Standards, 5th Edition (Palliative Care Australia, 2018) as a founding document for this work.

Joanna Harper
Director, Harper Devine Ltd

Professor Rod MacLeod
MNZM, Honorary Professor in the Sydney Medical School

Professor Sue Hanson
National Director Clinical Services, Little Company of Mary Health Care Ltd

Hospice New Zealand Governance Group:

Jan Clark, Consumer representative
Cathy Cummings, Director, DAA Group
Frans Dellebeke, CEO , Nelson Tasman Hospice
Clare Randall, CEO, Arohanui Hospice
Jane Rollings, Hospice Palliative Care Service Manager, Nurse Maude Hospice
Craig Tamblyn, CEO, Hospice Waikato

Te Rōpū Taki Māori (Hospice New Zealand)

Hospice New Zealand Working Party members:

Denise van Aalst, Clinical Manager, Hospice Southland
Annette Finlay, Quality & Risk Coordinator, Privacy Officer & Māori Advisor, Nurse Maude Hospice
Becky Gardiner, Director of Human Resource & Operations, Waipuna Hospice
Diane Greenwood-Havea, Family Support Team Leader & Counsellor, Te Omanga Hospice
Elizabeth Lee, Quality & Safety Manager, North Haven Hospice
Dr Elizabeth Morgan, Palliative Medicine Specialist, Hospice Marlborough
Sarah Nichol, Quality Coordinator, Cranford Hospice
Belinda Watkins, General Manager, Hospice Mid Northland

Hospice New Zealand Reference Group members:

Eleanor Barrett, Occupational Therapist, Te Omanga Hospice
Alison Brown, Quality & Risk Coordinator, Hospice Waikato
Janine Ewan, CEO Clinical Services, Dove Hospice
Amanda Gill, Clinical Quality Coordinator, Arohanui Hospice
Peter Godden-Steele, Director of Nursing & Clinical Support Services, Te Omanga Hospice
Vicki Telford, CNS for Aged Residential Care & End of Life Education Facilitator, Nurse Maude Hospice
(Members' roles at the time of their participation)

The pilot hospice sites:

Hospice Southland
Rotorua Community Hospice
Te Omanga Hospice
Totara Hospice South Auckland

Copyright

For more information please contact:

Hospice New Zealand
PO Box 11557
Wellington 6142
Telephone +64 4 3810266

He kōrero whakataki

Introduction

The population of Aotearoa New Zealand is ageing, and people are living longer with the potential for multiple comorbidities, long-term conditions and complex health and social care needs. This requires change and development of health and social care services to meet the challenges, at a clinical and governance level. Quality palliative care will be essential to meet the increasing needs of people and their family and whānau.

Palliative care involves care for people of all ages with a life-limiting or life-threatening condition, aiming to optimise a person's quality of life and supporting families and whānau where needed.

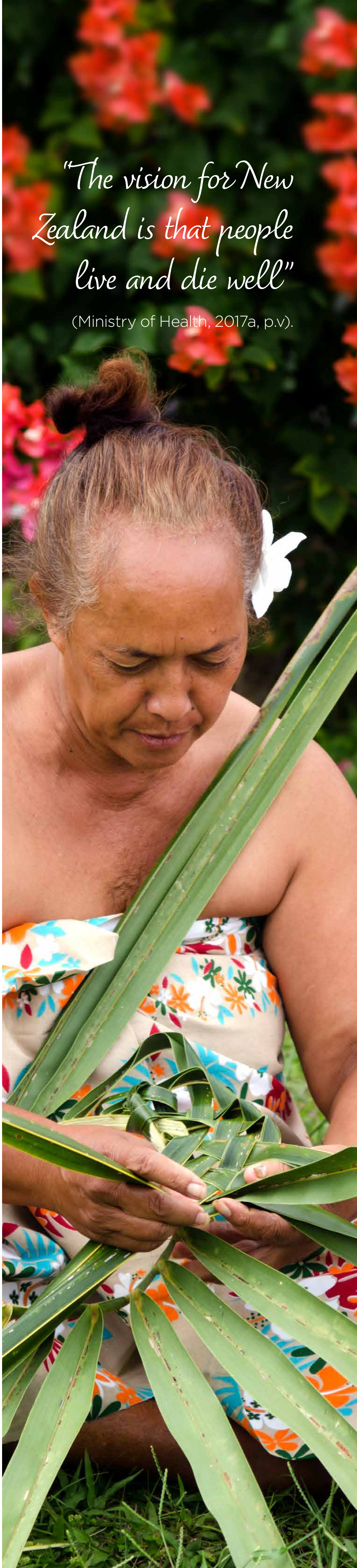
"It is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications".

(World Health Organisation, 2018)

Palliative care needs to be person-centred[1] and available when it is needed, regardless of diagnosis, and in the setting of choice. This approach will require collaboration and partnership between services and providers, including aged residential care, primary health, community support and hospital. Care needs to be respectful, empathetic, compassionate, effective and culturally appropriate for all people. This requires innovation, flexibility, resources, a skilled and competent workforce, and care based on evidence and research.

This is the fourth edition of the Hospice New Zealand Standards for Palliative Care, enhancing and building on previous versions[2]. They have been developed in consultation with the member hospices.



"The vision for New Zealand is that people live and die well"

(Ministry of Health, 2017a, p.v).

---

[1] **Person-centred:** is a concept that respects the cultural needs, preferences, values, beliefs, relationships and life experience of each person. It involves a mutual relationship between the person and the team and places the person in the centre of all planning for individualised care and services. Family and whānau should be considered, and involved where possible, in this process.

[2] See third version – *Hospice New Zealand Standards for palliative care. Quality review programme and guide* (Hospice New Zealand, 2012)

The new Hospice New Zealand Standards for Palliative Care (Standards) align with the principles of the *Treaty of Waitangi* (1840). The principles of partnership, participation and protection underpin the values and intent of the Standards for the people, families and whānau, and the Hospice services, staff and volunteers.

The Standards have been developed to support all member hospices to provide quality palliative and end-of-life care and services for people and their families and whānau.

One of the key aims is to capture the change and development seen within palliative care in the past ten to fifteen years, including emerging evidence, technology, models of funding and services, expectation and need, and language.

There are some key changes to the new Standards.

There are nine standards that address the areas of clinical care services and governance. The six clinical standards describe systems and enablers for the delivery of clinical care and the three governance standards describe expectations of the organisation, quality and research, and support for staff and volunteers.

It is recognised that there are local and regional difference in size, service model, funding, capacity and capability across the hospices, but the Standards can be applied by all Hospice services. For some, the Standards will be core but there will aspirational components for those seeking to develop and improve their service/s.

Guidance has been developed to assist users to interpret and implement the Standards and there is mapping to align with the *Health and Disability Services Standards* (Standards New Zealand, 2008) and the *Home and Community Support Sector Standard* (Standards New Zealand, 2012).

The term *'Hospice service'* has been adopted to describe all hospices that are members of Hospice New Zealand. This recognises that all Hospice services are specialised services that focus on providing hospice and palliative care as their core business. Some Hospice services deliver specialist level care services provided by a specifically qualified professional team, some are in the process of developing their specialist status, and some access specialist support/expertise from other services[3].

The profile of the care teams working for Hospice services varies depending on the model of care, funding arrangements, and the capacity and capability of the Hospice service. There are a number of possible profiles for Hospice teams; interdisciplinary, multidisciplinary, and at times a combination where Hospice services are working in a shared cared model. The Standards use the generic term *'team'* to capture this variance[4].

Hospice services will support, and work with, a range of services and providers to deliver palliative care services to their community. This includes, but is not limited to, aged residential care, primary health, community support services and hospitals. For the Standards, these other services, providers, partners and colleagues will be referred to as *'other service providers'*.

[3] Refer to the *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand* (Ministry of Health, 2013)

[4] Refer to glossary for the full descriptions of interdisciplinary and multidisciplinary

Te pūtake

Purpose

The vision for the Standards is that all people in New Zealand have equitable access to quality palliative care as they approach the end of their life and die.

The practice of continuous quality improvement is an opportunity to reflect on what services do well, validate the care and services provided, continue with what works well, refine what is not working so well and to identify opportunities to develop new services. This practice includes, but is not limited to, outcome measurement, audit, benchmarking and assessment. This activity may include internal, regional and national activity.

The Standards are outcome-focused and articulate an expectation of what Hospice services should provide to meet the palliative and end-of-life needs of their community. They are applicable to all settings where a person may choose to live or receive care and services.

The Standards will promote, support, guide and inform continuous quality improvement practice and planning for all Hospice services. They do not aim to duplicate, but to align with, existing national standards that Hospice services are required to undergo e.g. certification of health care services[5]. For the Hospice services that are not required to undergo a certification process, the Standards will provide a framework and guidance to assist with their continuous quality improvement programme and the development of their service.

The Standards will provide a framework for the future development of an assessment and measurement framework. Accreditation and certification agencies and bodies will be asked to use the Standards as part of their assessment and survey of Hospice services.

Te tirohanga whānui

Scope

The Standards have been written for Hospice services providing care and services for adults with a life-limiting illness who require hospice palliative care in the setting of their choice.

It is hoped the Standards will be adopted and used to complement the care provided by other service providers.

Specialist paediatric care is not within the scope of the Standards. The National Paediatric Palliative Care Clinical Network leads and provides national clinical oversight and guidelines for integrated paediatric palliative care in New Zealand[6].

---

[5] Refer to Ministry of Health website for information on HealthCert – www.health.govt.nz/our-work/regulation-health-and-disability-system/certification-health-care-services

[6] See Starship website www.starship.org.nz/for-health-professionals/new-zealand-child-and-youth-clinical-networks/paediatric-palliative-care-clinical-network/

Te mahi ngātahi i te iwi Māori

Working with Māori people

These standards align with the principles of the *Treaty of Waitangi* (1840) to work collaboratively with Māori to provide the best care and outcomes for Māori patients/tūroro and whānau.

Hospice New Zealand acknowledges the unique partnership with Māori as tangata whenua of Aotearoa New Zealand. Hospice New Zealand acknowledges that hospices have a responsibility to ensure that quality compassionate palliative care is available and delivered to Māori patients/tūroro and whānau, alongside the care delivered to all members of the community.

Engagement at a national and local level with respected representatives of Māori will result in a relationship or a partnered process. Through partnership we can remove barriers to hospice services that may exist for Māori. Through the implementation of the Standards, hospices can improve the quality of the experience for Māori.

The holistic approach of palliative care has an affinity with the Māori Health Model, Te Whare Tapa Whā (the four-sided house) – all four sides are necessary to ensure strength and symmetry. It describes a balance between taha wairua (spiritual wellbeing), taha hinengaro (intellectual and emotional well-being), taha tinana (physical well-being) and taha whānau (family/human relationships). There is the opportunity to explore how these dimensions affect all people in hospice care, but caution must be applied to ensure that staff do not assume particular meanings for Māori, simply because the dimensions are familiar from the perspective of their own cultural view.

Information on other Māori models can also be found in the Wairuatanga module of the Hospice New Zealand Foundations of Spiritual Care education programme. Local iwi/hapū/whānau may also have variations on the health care models which they practise. Hospices can assess the capacity they have internally to develop relationships with local iwi and Māori communities and expand the support to the model of care. Resources have been identified in the Standards that will support this expansion of the approach and may lead to the development of tools such as tikanga guidelines, Māori service plans, local Māori knowledge, education and training.

The Standards will guide services to continue to develop models of care that begin to address the pathways for action set out in *He Korowai Oranga: Māori Health Strategy* (Ministry of Health, 2014). These national standards encourage increased Māori participation in decision-making, planning and delivery of health services; thereby improving access and supporting whānau ora (Māori health and wellbeing).

Te Whare Tapa Whā

Durie, M. (1998). *Tirohanga Māori: Māori health perspectives*. Auckland: Oxford University Press.

We would like to acknowledge Mary Potter Hospice for allowing us to adapt and use excerpts from their staff induction resource.

Taha wairua

Spiritual wellbeing is the capacity for faith and/or inner strength. For Māori it includes a deep appreciation of the wider natural environment and relationships with others. The spiritual essence of a person is their life force. This determines us as individuals and as a collective, who and what we are, where we have come from and where we are going. This is about how we see ourselves in this universe, our interaction with and perception of others.

Taha hinengaro

Emotional and mental well-being is the capacity to communicate, to think and to feel mind and body are inseparable. Thoughts, feelings and emotions are integral components of the body, spirit and soul.

Taha tinana

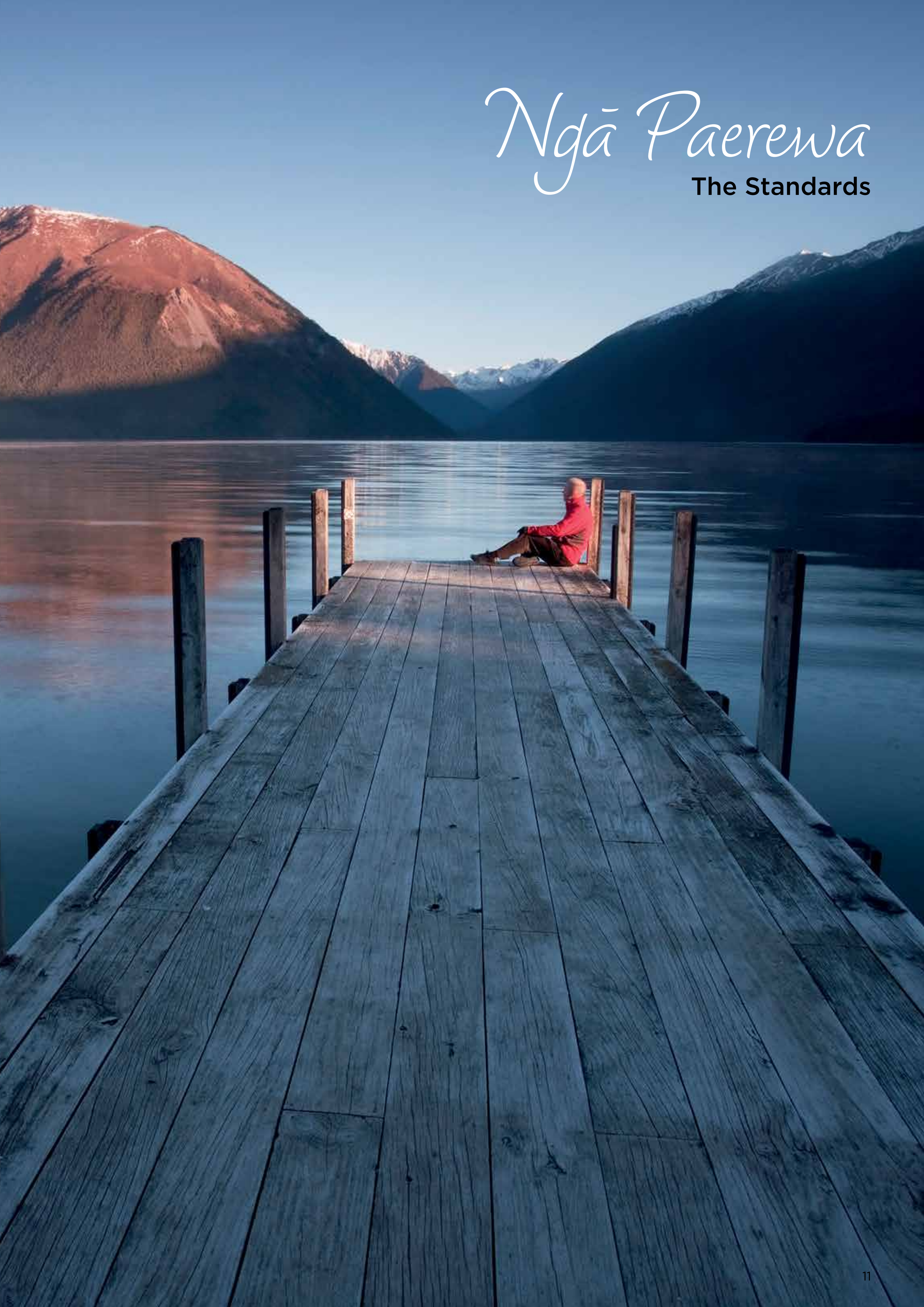
Physical well-being has the capacity for physical growth and development, or deterioration. Our physical being supports our essence and shelters us from the external environment. For Māori the physical dimension is one aspect of health and wellbeing and cannot be separated from the aspect of mind, spirit and family.

Taha whānau

Family and human relationships provide a belonging, to care and to share, where individuals are part of wider social systems. Whānau provide us with strength to be who we are and the responsibilities to care for others. This is the link with our ancestors, our ties with the past and the present and the future.

Ngā Paerewa

The Standards



Ngā Paerewa

The Standards

Paerewa 1: Te arotake hiahia **Standard 1: Assessment of needs**	Initial and ongoing assessments are comprehensive and person-centred, and incorporate the person's physical, psychological, cultural, social and spiritual experiences, needs, preferences and priorities.
Paerewa 2: Te whakarite mahere manaaki tāngata **Standard 2: Developing the care plan**	The team works in partnership with the person, their family, whānau and carers, to communicate, plan, set goals and make informed decisions about their care plan.
Paerewa 3: Te manaaki tāngata **Standard 3: Providing the care**	Care provided is empathetic, informed by evidence, and aligned with the person's values, culture, goals and preferences as documented in their care plan.
Paerewa 4: Te tautāwhi whānau me ngā kaitautoko **Standard 4: Supporting and caring for the family, whānau and carers**	The person's family, whānau and carers' needs and preferences are assessed and they are provided with appropriate support, guidance and resources.
Paerewa 5: Te whakawhitinga o ngā ratonga **Standard 5: Transitions within and between services**	Palliative care is accessible to all people who need it and it is integrated and coordinated across the person's experience to ensure seamless transition within and between services.
Paerewa 6: Te tautoko me te manaaki pāpouri **Standard 6: Grief support and bereavement care**	The person at the centre of care, and their family, whānau and carers, have access to grief support and bereavement care services and they are provided with information about loss, grief and bereavement.
Paerewa 7: Te ahurea o te tari **Standard 7: Culture of the organisation**	The Hospice service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative and end-of-life care.
Paerewa 8: Te whakapakari kounga me te rangahau **Standard 8: Quality improvement and research**	Hospice services are engaged in quality improvement and research to improve service provision and the development of palliative and end-of-life care.
Paerewa 9: Ngā tohu me ngā mahi whakangungu a ngā kaimahi **Standard 9: Staff qualifications and training**	Staff and volunteers are skilled, competent, qualified, and engaged in continuing professional development appropriate to their role and the capability of the Hospice service.

Me pēhea e whakamahi tika ai ngā paerewa

How to use and interpret the Standards

The Standards have been developed to support all Hospice services to deliver quality palliative care for the person and their family, whānau and carers.

They include core and aspirational components that will assist and guide continuous quality improvement for all Hospice services regardless of size, capacity, capability or stage of service development.

The Standards are outcome-focused. Hospice services are advised that the intention is not to be prescriptive, but to consider the different and appropriate ways they can meet the outcomes and improve their service.

The Standards should be used and implemented in accordance with current legislation, codes and relevant local, regional and national policy and contractual obligations[7].

A glossary and list of resources is provided to support the interpretation of the Standards.

It is not the intention to duplicate other quality and regulatory processes. Therefore, each Standard has been specifically mapped against the *Health and Disability Services Standards* (Standards New Zealand, 2008) and the *Home and Community Support Sector Standard* (Standards New Zealand, 2012).

The nine Standards are divided into two categories:

Clinical Standards (1-6) describe systems and enablers for the delivery of clinical care.

Governance Standards (7-9) describe expectations of the organisation, quality and research and support for staff and volunteers.

The Standards should be viewed and used as a full suite of interrelated Standards. Specific linkage has been indicated as a guide within each Standard.

---

[7] A list of New Zealand legislation and codes is available on pages 44 and 45.

Ngā paerewa pairuri tāngata

Standards for Palliative Care

Care Standards

Standard 1
Assessment of needs

Standard 2
Developing the care plan

Standard 3
Providing the care

Standard 4
Supporting and caring for family, whānau and carers

Standard 5
Transitions within and between services

Standard 6
Grief support and bereavement care

Governance Standards

Standard 7
Culture of the organisation

Standard 8
Quality improvement and research

Standard 9
Staff qualifications and training

The purpose of each component of the Standards

Standard	This is the specific Standard.
Intent of the Standard	This provides detail and explanation to assist with interpretation of the Standard.
Standard Elements	This is a series of criteria or outcomes to which services are encouraged to aspire to meet the Standard.
Guidance	This is a list that aims to assist and guide services to address the elements of the Standard.
Prompt questions	These questions provide a focus for the team to discuss and ask themselves how they are meeting the elements of the Standard.
Mapping	This aims to assist services to identify alignment with the *Health and Disability Services Standards* (Standards New Zealand, 2008) and the *Home and Community Support Sector Standard* (Standards New Zealand, 2012) and to avoid duplication.

Te whakamahi paerewa ki ngā iwi katoa

Applying the Standards to all populations

Palliative and end-of-life care should be available to all people who need it. Aotearoa New Zealand has a diverse population, which includes groups of people with a unique set of personal, cultural and health circumstances, expectations and needs. Some groups may be considered especially vulnerable, marginalised, at risk, or potentially underserved within the healthcare system. These groups often experience poor health outcomes. Individuals in these groups are likely to have complex needs associated with a chronic and long-term condition which may further complicate their care as they approach the end of life.

It important that palliative and Hospice services respect and understand difference and diversity. To work with these groups, and meet the needs of the individual, and their family, whānau and carers, Hospice services need to work in partnership and collaboration with specific support groups and other service providers who may have been involved with the person for many years.

Work has been done to identify and develop useful models and frameworks that assist and guide services who are working with different groups of people. The groups include, but are not limited to, those described below[8].

Māori people

See page 8.

People from Pacific Island nations

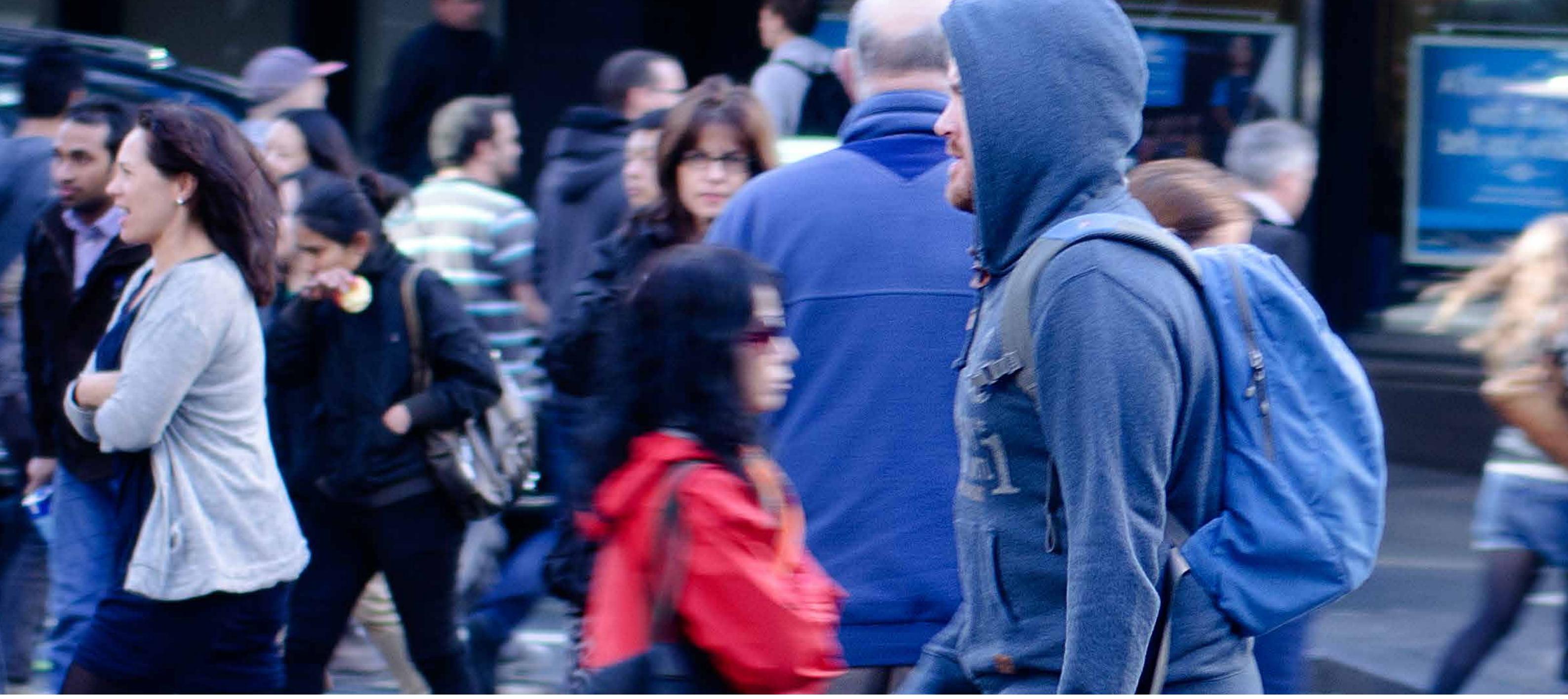
Pacific peoples in Aotearoa New Zealand are diverse – culturally and socially. Understanding Pacific people's personal perceptions and cultural beliefs and values about their health is crucial to understanding the use of health services and expectations of quality care for individuals, families and communities. Pacific models of health care have been developed which recognise Pacific world views, beliefs and values about health. Pacific principles include respect for Pacific culture, valuing family and communities, quality health care and working together/integration. Hospice services need to ensure they consult and collaborate with Pacific peoples to ensure access to appropriate cultural support and advocacy.

People with a culturally and linguistically diverse backgrounds

Culturally and linguistically diverse groups in Aotearoa New Zealand may include, but are not limited to, Pacific peoples, Asian peoples, Middle Eastern, Latin American, African and Continental European groups. People from different cultural backgrounds may have a different language, cultural beliefs, values, customs, experience, understanding and expectations which may impact on how they approach the end of life. The family and support structure may be different. Access to interpreters should be considered to facilitate interactions and to ensure the needs of a person and their family are understood. Hospice services need to collaborate with cultural and ethnic groups to understand the needs of their people, plan services and to reduce disparity and barriers to access. There may be specific immigration and/or funding/payment issues involved. Services and care will need to be flexible and negotiated with the person and their family. Cultural knowledge, competence, awareness and sensitivity is essential when working with people from different cultural backgrounds.

---

[8] A list of resources to support this section is available on page 47.



People living with a chronic or long-term condition

People who live with a chronic or long-term condition may benefit from a palliative approach during their illness or disease. These conditions include those that are aged related, cancer, diabetes, heart, renal, respiratory and neurological conditions. A palliative approach may work with any active ongoing care and treatment to meet the needs of the person and their family and whānau and carers. Advance care planning and decisions about future care will be important to manage potential crises or distress. Shared care with Hospice services or hospital palliative care services may be necessary to address complex needs such as symptom management or psychosocial or spiritual support.

People who live in an aged residential care facility

For some people, an aged residential care facility will be their home. Some people live in a facility for many years before needing a palliative approach, but an increasing number of people are admitted for palliative and end-of-life care. The level and complexity of needs for the residents are increasing and requires knowledge, skills and competence in palliative and end-of-life care. It is important that people living in a facility have access to an appropriate level of care and support from the aged residential care staff, the general practitioner and other primary care services. The Hospice service needs to work in partnership with the facility staff to ensure access to specialist care and support to meet the complex needs of the person and their family and whānau. Support and education for the facility staff should be available and provided by the Hospice service.

People who live in an institution or people experiencing homelessness

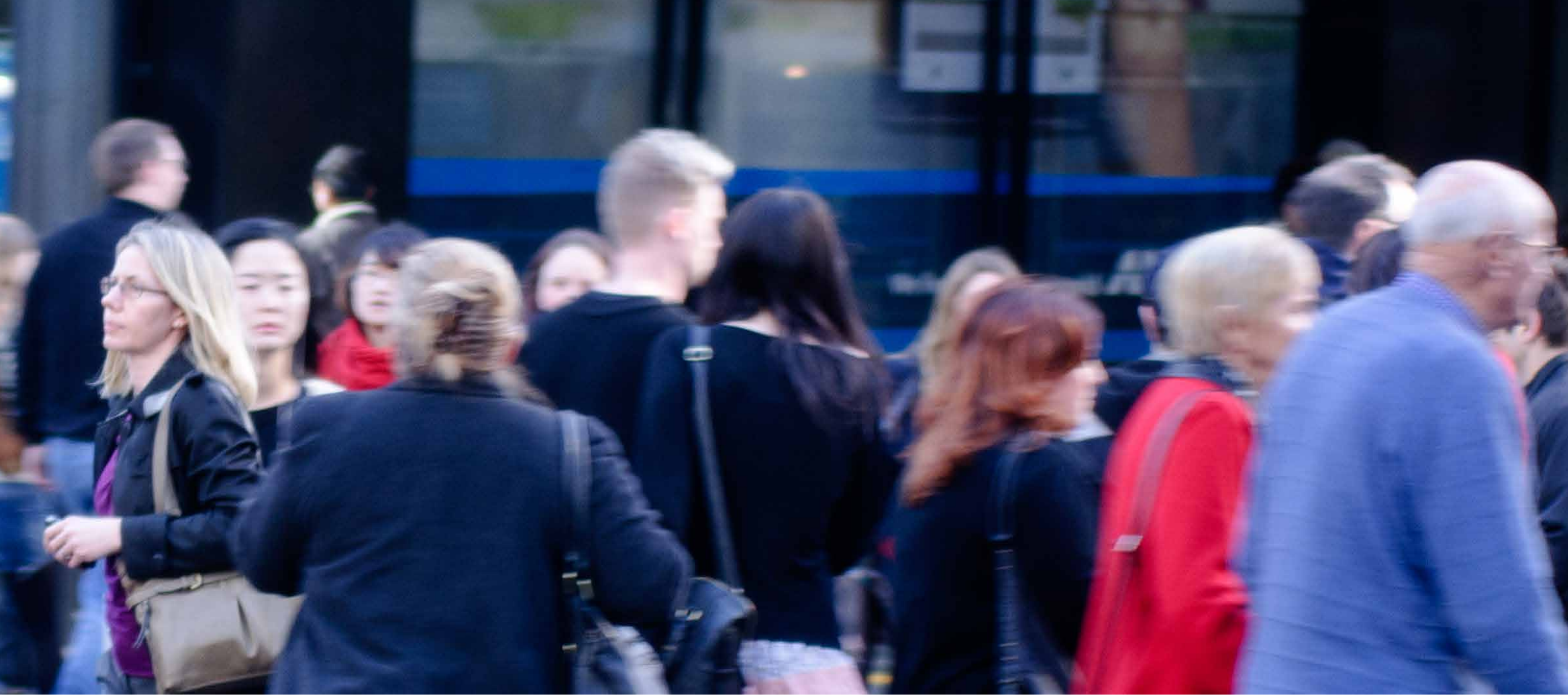
Some people die in institutions such as prisons, group homes or hostels. Some people may be homeless, displaced, migrants or refugees. These people may be transient, and it may be hard to maintain an ongoing relationship. It is important that palliative and end-of-life services are available and flexible to meet the needs of these potentially vulnerable people. To ensure the needs can be appropriately met, Hospice services need to support and work in partnership with other services, agencies or groups that may be involved.

People living with disability

People may be living with a physical, sensory, neurological, psychiatric, intellectual disability or other impairment. It is important to recognise and consider the unique, and sometimes complex, issues for people with a disability. Some people with a disability will need assistance to understand their diagnosis and its impact on their current needs and aspirations. It is also important to consider the family and whānau and others who may be supporting them. Existing health and disability support services involved in a person's care will need to be a part of the care planning process and Hospice care may need to be delivered in collaboration and partnership.

People living with dementia

People living with dementia can experience an unpredictable course of the disease, a range of complex symptoms, limited or no capacity to set goals and make decisions, challenges with communication, in addition to a lack of community understanding of the condition. Advance care planning will be important to ensure the person's wishes and preferences are honoured. A legal substitute decision-maker is often required. People living with dementia may struggle to access palliative care appropriate to their (often) complex needs. Hospice services must be flexible and work collaboratively with a wide range of other service providers to provide appropriate care to the person living with dementia in a range of care settings, including the person's home and aged residential care. The family and whānau will also need support as their relationship and role can be complex and challenging both physically and emotionally. Education and training for staff and volunteers will be important. Hospice and palliative care services will increasingly encounter people for whom dementia is a significant comorbidity that will impact upon their management in a palliative care setting.



People living with mental health illness

People living with a mental health illness may experience comorbidities and other health issues and may be involved with a range of existing services. Access and engagement with health services and the health team can be challenging. There may be issues with their legal capacity to make decisions (or choices). Providing services for people with a mental health illness can create wider challenges for Hospice services. People with mental health needs may have poorly met social, housing, income and support needs. To achieve optimal outcomes for people with mental illness, the Hospice service may need to develop partnerships with mental health services, the general practitioner and primary health services, and other community-based services.

People with limited or no capacity to make informed choices

For a person to make an autonomous, informed and competent choice (or decision) in their own best interest they need to be fully informed of the facts and probabilities, able to understand the information, able to make a voluntary and reasoned choice, and to be able to communicate that choice. Some people may be able to make simple choices on a day-to-day basis, but then have limited or no capacity to make informed and competent choices about more complex and important aspects of their care and treatment, including type and place of care and services. This may include people with dementia, intellectual disability or an intracerebral malignant disease. It will be important that a person's legal capacity to make decisions and choices is identified and established in a sensitive manner. This is not a single event and may need to be revisited as changes occur. Where necessary, the input of the nominated and legal substitute will need to be enacted.

Children and adolescents with a life-limiting condition

Palliative care for children and adolescents requires an integrated and flexible person-centred approach to meet their unique needs. Their multi-dimensional needs are influenced by their developmental stage and the nature of the condition which can be complex with a long trajectory and uncertain prognosis. Support for the family and whānau is important; they will be dealing with progressive deterioration and the potential death of their child, which may be accompanied by a range of other complex social and financial needs. Informed consent for a minor can be a specific issue for the assessment and care planning process.

A palliative approach for children and adolescents may be required throughout the trajectory of their illness or disease, regardless of whether they are receiving active treatment. They are likely to have strong links with the general practitioner, primary health care team and community services. Specialist paediatric services may be actively involved or involved in a consultative and advisory role. Hospice services may be involved in the care of children and adolescents, but this is usually in partnership with the other services and providers.

People who are lesbian, gay, bisexual, transgender, queer or questioning, and intersex (LGBTQI+)

LGBTQI+ people continue to experience misunderstanding, prejudice, discrimination, isolation, marginalisation, harassment and abuse leading to reduced health and well-being. They may suffer from chronic and life-limiting conditions that require a palliative approach and at times specialist hospice and hospital palliative care.

Palliative care services for LGBTQI+ people should be accessible and inclusive; they should be culturally appropriate, safe, respectful, non-judgemental, welcoming and acceptable to the person and their self-designated family, whānau, friends, carers and support networks. Partnership between the person's existing health and support services and specialist services will be important to meet their needs. Knowledge and an understanding of current language and terminology will ensure safe and appropriate professional relationships and communication for assessment and care planning. Hospice services need to work and consult with local LGBTQI+ people, groups, forums and communities to ensure services are acceptable and appropriate for individuals to access. Education and training for staff and volunteers is important.

Paerewa 1: Te arotake hiahia

Standard 1: Assessment of needs

Initial and ongoing assessments are comprehensive and person-centred, and incorporate the person's physical, psychological, cultural, social and spiritual experiences, needs, preferences and priorities.

Intent of the standard

A comprehensive and holistic assessment, led by the person, is the foundation for providing palliative and end-of-life care. It is an integral and important process to ensure the services and the care meets the unique needs of the person.

Assessment for all people should be based on a person-centred approach. It establishes their unique physical, psychological, cultural, spiritual and social needs, and their preferences and priorities, which will be influenced by context and past experiences. Assessment for those that identify as Māori should be based on a Māori model of health and wellness. The approach and model of care may need to be adapted for other specific groups.

The assessment occurs on initial presentation to the service. It should involve a face to face meeting, or meetings, paced so as not to overwhelm the person, or their family, whānau and carers if they are involved. The process should be coordinated, and collaborative, and may involve several members of the clinical team, and in some cases other service providers.

The assessment information provides a baseline for regular reassessment as the person's condition and situation changes. The information and identified goals will guide and inform the development of the care plan.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

1.1 The clinical team conducts an initial and ongoing holistic assessment.

1.2 The cultural and spiritual context for the person, their family, whānau and carers is assessed for its importance and impact on their needs.

1.3 The assessments are coordinated and shared with other service providers as required to avoid duplication and to minimise stress on the person, their family, whānau and carers.

1.4 Evidence based assessment tools are used to identify people approaching the end of life as well as those that are imminently dying.

1.5 The person's needs are reassessed and documented as their condition and needs change.

1.6 Initial and ongoing assessments identify the unique needs and goals of care and are documented in the person's clinical record and inform the care plan.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

Do we have policies and guidelines to support and guide the assessment process?

How do we ensure confidentiality and privacy and how do we gain consent?

Who coordinates the first assessment and who is involved?

How do we know the assessment is reflecting a person-centred approach?

How is the assessment information documented and shared with the clinical team and other service providers?

How do we provide 24-hour access to an assessment?

How often do reassessments occur? Who is involved?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard Two: Developing the care plan and Standard Four: Supporting and caring for the family, whānau and carers

Policies and procedures

Patient record system

Evidence of a person-centred approach

Documented consent

Use of genogram to identify relationships

Documentation of advance care plans and end-of-life wishes

Use of translators

Evidence of a Māori model of care e.g. Te Whare Tapa Whā, Te Wheke, Te Pae Mahutonga[9]

Evidence of a Pacific model of care e.g. Fonofale Model of Health, Fonua: A Pasifika Model for Health Promotion[10]

Evidence that the model of care is adapted to the unique needs of all people e.g. children and adolescents, people with dementia

Access to a clinical team with specialist qualifications and experience in hospice palliative care

Other service providers are involved in the assessment as required

Further expertise is accessed if required e.g. oncology, paediatric, gerontology

Evidence of best practice and the use of validated assessment tools

Admission criteria

Policy and guidelines for managing and responding to referrals; including single point of entry, triage, expected response times and when a person is declined

Access to an urgent assessment is available 24 hours a day, seven days a week

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.3:2008 – Health and Disability Services (Core) Standards – Continuum of service delivery

- **Standard 3.1** – Consumers' entry into services is facilitated in a competent, equitable, timely, and respectful manner, when their need for services has been identified.
- **Standard 3.2** – Where referral/entry to the service is declined, the immediate risk to the consumer and/or their family/whānau is managed by the organisation, where appropriate.
- **Standard 3.3** – Consumers receive timely, competent, and appropriate services in order to meet their assessed needs and desired outcome/goals.
- **Standard 3.4** – Consumers' needs, support requirements, and preferences are gathered and recorded in a timely manner.
- **Standard 3.9** – Consumer support for access or referral to other health and/or disability service providers is appropriately facilitated or provided to meet consumer choice/needs.

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 2: Organisational Management

Outcome: Consumers receive services that comply with legislation and are managed in a safe, efficient, and effective manner.

Standard 4: Service Delivery

Outcome: Consumers receive services that contribute to their agreed outcomes, and that support their independence, safety and well-being.

---

[9] See Ministry of Health website – www.health.govt.nz/our-work/populations/maori-health/maori-health-models

[10] See Hauora website – www.hauora.co.nz/pacific-health-promotion-models/

Paerewa 2: Te whakarite mahere manaaki tāngata

Standard 2: Developing the care plan

The team works in partnership with the person, their family, whānau and carers, to communicate, plan, set goals and make informed decisions about their care plan.

Intent of the standard

The person should be supported to be an active partner in the planning of their care as they approach and reach the end of life. The family, whānau and carers should be included to the extent agreed by the person.

Where the person is not able to participate in care planning or decision-making, it is important that a legal substitute decision-maker (Enduring Power of Attorney or Welfare Guardian) is identified. Where there is no substitute identified, the person's best interests are determined, consistent with any advance communication of goals and preferences, and in accordance with relevant legislation and/or policy.

The comprehensive assessment, and regular reassessments, provide the foundation for setting the person's unique goals and developing the care plan. The person's experience will be unique, and their needs and preferences may change as they approach the end of life. This will require regular review and adjustment. The care plan should reflect the complexity of need and be documented and communicated across the clinical team and any other service providers involved.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

2.1 The person's documented care plan is culturally appropriate and reflects the initial and ongoing assessments and identified needs.

2.2 The person is provided with information to support informed participation in care planning and decision-making.

2.3 The person is supported to identify, plan, document and update goals of care.

2.4 The care plan considers the person's social, cultural, spiritual and community networks.

2.5 Systems are in place to manage decision-making and care planning, including when the person does not have the capacity to participate.

2.6 The type, place and provider/s of care are negotiated with the person and their family, whānau and carers and preferences are met where possible.

2.7 Care plans incorporate management of care for out of hours emergencies and support, including certification of death and the care and collection of the body/tupapaku.

2.8 Care plans reflect the needs of the person, and their family, whānau and carers in the last days of life[11].

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

Do we have policies and guidelines to support and guide the care planning process?

How is the assessment information used to plan care?

Are the care plans person-centred?

What information is available and provided to support people to make decisions and plan their care?

What tools are used to plan and provide care for the last days of life?

How do we manage a situation where a person lacks the capacity to make decisions?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard One: Assessment of needs, Standard Three: Providing the care and Standard Four: Supporting and caring for the family, whānau and carers

Policies and procedures

Patient record system

Documented consent

Systems and processes to share the care plan within the team

Evidence of the person's participation in the planning of care

Evidence and record of advance care planning

Information is available and appropriate to the person's level of health literacy

Evidence that the care plan reflects the unique needs identified in the assessment

Evidence of regular review, evaluation and necessary adjustment of the care plan

The care plan is available to the team 24 hours a day, seven days a week

Systems to share and communicate the care plan with other service providers involved in the provision of care

Regular team meetings

Formal planning meetings with the person, and their family, whānau and carers

Agreements and partnerships with other service providers where a shared care model of care is in place

Systems in place to identify, monitor and manage actual/potential issues and risks

Agreements and partnership with local cultural and spiritual groups

Access to specific groups that address the needs of vulnerable populations

End-of-life care planning process e.g. use of *Te Ara Whakapiri: Toolkit*[12]

Anticipatory care planning for out of hours e.g. ambulance plans

Evidence of assessing a person's capacity for decision-making

Record of substitute decision-maker – Enduring Power of Attorney or Welfare Guardian

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.3:2008 – Health and Disability Services (Core) Standards – Continuum of service delivery

- **Standard 3.1** – Consumers' entry into services is facilitated in a competent, equitable, timely, and respectful manner, when their need for services has been identified.
- **Standard 3.3** – Consumers receive timely, competent, and appropriate services in order to meet their assessed needs and desired outcome/goals.
- **Standard 3.5** – Consumers' service delivery plans are consumer focused, integrated, and promote continuity of service delivery.
- **Standard 3.8** – Consumers' service delivery plans are evaluated in a comprehensive and timely manner.
- **Standard 3.9** – Consumer support for access or referral to other health and/or disability service providers is appropriately facilitated or provided to meet consumer choice/needs.

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 4: Service Delivery

Outcome: Consumers receive services that contribute to their agreed outcomes, and that support their independence, safety and well-being.

---

[11] *Te Ara Whakapiri: Principles and guidance for the last days of life* is a statement of guiding principles and components of care for adults in the last days (Ministry of Health, 2017b)

[12] *Te Ara Whakapiri Toolkit: Care in the last days of life* includes a set of templates, checklists, flowcharts, tools and patient resources (Ministry of Health, 2017c).

Paerewa 3: Te manaaki tāngata

Standard 3: Providing the care

Care provided is empathetic, informed by evidence, and aligned with the person's values, culture, goals and preferences as documented in their care plan.

Intent of the standard

The provision of safe, quality care is person-centred and based on the comprehensive clinical assessment, goals and care plan.

The team has the necessary knowledge, skills, expertise and attributes required to meet the identified needs of the person. The care is based on the best available evidence.

Effective care can support the person to live as well as possible to the end of their life. The comfort and the relief of suffering for the person should be a priority. All symptoms need to be pre-empted and managed, but when distress does occur, there should be an empathetic, timely and effective response by the team.

Where the person's preferences cannot be met, the team is expected to communicate empathetically and compassionately with the person, their family, whānau and carers. Alternative options to support the person's goals should be discussed, negotiated and communicated.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

3.1 Compassionate, culturally appropriate care is provided as documented in the care plan.

3.2 The most appropriate members of the team, family, whānau and carers, provide care to meet identified needs.

3.3 Specialist palliative care advice and expertise is available or accessed as required.

3.4 Care is informed by the best available evidence in accordance with legislation, regulation and professional practice guidelines and standards.

3.5 Advice and support are provided to other service providers involved in the person's care.

3.6 Variance from the negotiated care plan is discussed, recorded and communicated.

3.7 The team recognise emerging risks and anticipate and respond appropriately to any change in the person's needs.

3.8 The person, and the family, whānau and carers, have as much information as they want.

3.9 The care is evaluated, updated, and changes are documented.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

- How do we evaluate/measure that the intent of this standard is being met?
- Do we have clinical policies and procedures that are based on the best available evidence?
- How do we demonstrate compassion and empathy?
- Do we have a clinical team that is qualified and experienced to provide the level of care for the people accessing the service? How do we access further expertise?
- Does the care plan direct, guide and support the care provided?
- What do we do if we cannot meet the identified need and care plan?
- How do we keep people informed and up to date?
- How do we evaluate the effectiveness of the care provided?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard One: Assessment of needs, Standard Two: Developing the care plan and Standard Four: Supporting and caring for the family, whānau and carers

- Policies and procedures
- Tikanga Māori guidelines
- Use of guidelines for other specific cultures and groups
- Documented consent
- Patient record system
- Documented evaluation of care
- Referral process to support access to the range of services required to support the planned care package
- Systems and agreements to access specialist palliative care advice as required
- Systems and agreements to support shared care with other service providers
- Care is provided by an appropriately qualified and experienced team
- Specialist advice and support is available 24 hours a day, seven days a week; this may be provided by telephone or visiting service
- Support and education is available to other providers
- Regular documented meetings with the team involved in the provision of care, including other service providers as required
- A coordination model of care
- Care is aligned and based on the assessment and care plan
- Care plan is easily accessible to all providers of care
- Care is provided as documented in the care plan
- Any change or variance to the care plan is documented and communicated
- Best clinical practice, guidelines and protocols
- Clinical indicators and benchmarking
- Clinical audit
- Clinical outcome measurement tools
- Systems for communication with other service providers
- Resources for people and their family and whānau and carers e.g. verbal, written and digital
- Systems to record incidents and adverse events
- Systems and agreements for the provision of care 24 hours a day, seven days a week
- Process to identify and communicate gaps and barriers to care

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.3:2008 – Health and Disability Services (Core) Standards – Continuum of service delivery

- **Standard 3.3** – Consumers receive timely, competent, and appropriate services in order to meet their assessed needs and desired outcome/goals.
- **Standard 3.6** – Consumers receive adequate and appropriate services in order to meet their assessed needs and desired outcomes.
- **Standard 3.8** – Consumers' service delivery plans are evaluated in a comprehensive and timely manner.
- **Standard 3.9** – Consumer support for access or referral to other health and/or disability service providers is appropriately facilitated or provided to meet consumer choice/needs.

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 4: Service Delivery

Outcome: Consumers receive services that contribute to their agreed outcomes, and that support their independence, safety and well-being.

Paerewa 4: Te tautāwhi whānau me ngā kaitautoko

Standard 4: Supporting and caring for the family, whānau and carers

The person's family, whānau and carers' needs and preferences are assessed and they are provided with appropriate support, guidance and resources.

Intent of the standard

The person's family, whānau and carers play a unique and important role in providing a wide range of care. It can be rewarding but it can also be challenging at times. It is important that the team recognises and values their role and contribution and provides resources and support to build resilience and to manage potential distress.

It is recognised that there may be a number of people who identify themselves as family, whānau or carer. This may require each being assessed independently, establishing their individual needs and preferences, any risk factors, and supporting them to identify the level of care they are willing and able to provide. It is important the person confirms and agrees to their involvement in providing care and necessary communications.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

4.1 The initial assessment identifies members of the family, whānau and carers and this is reconfirmed as change occurs.

4.2 The needs, responsibilities, expectations, wishes, and desired level of involvement of the family, whānau and carers are assessed as change occurs.

4.3 A support plan, based on the before and after death needs, is developed and implemented with the family, whānau and carers.

4.4 The family, whānau and carers are informed to support their participation in care planning and delivery of care.

4.5 The family, whānau and carers are provided with information and a plan for emergency and out-of-hours situations.

4.6 The family, whānau and carers are provided with information on the signs and symptoms of approaching death and the steps required following death.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

Do we have policies and guidelines that specifically relate to family, whānau and carers?

How do we identify and involve members of the family, whānau and carers?

What is our system for documenting details and information about the family, whānau and carers?

How do we maintain confidentiality, privacy and consumer rights?

How do we support the family, whānau and carers to connect with their existing support networks?

What other services do we access to support the family, whānau and carers?

How do we address the needs of children?

How do we accommodate large family and whānau groups?

What information, resources and materials do we have specific to the family, whānau and carers? How do we check their understanding?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard Six: Grief support and bereavement care

Policies and procedures

Documented consent

Use of translators

Evidence of assessment of family, whānau and carers

Use of genogram to identify relationships

Carers are identified and recorded

System for recording and communicating the identified needs and support plan Note: this may include before and after the person's death and may be separate to the person's record

Systems and processes for referral and access to other agencies and providers

Out of hours planning e.g. ambulance plans

Resources and information available e.g. verbal, written and digital

Information is available and appropriate to the person's level of health literacy

Family and whānau meetings

Education for carer programme

Services to support children and adolescents

Information on how to access other services and support e.g. financial assistance

Access to respite and carer relief

Training and support programmes for family, whānau and carers

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.3:2008 – Health and Disability Services (Core) Standards – Continuum of service delivery

- **Standard 3.1** – Consumers' entry into services is facilitated in a competent, equitable, timely, and respectful manner, when their need for services has been identified.
- **Standard 3.3** – Consumers receive timely, competent, and appropriate services in order to meet their assessed needs and desired outcome/goals.
- **Standard 3.9** – Consumer support for access or referral to other health and/or disability service providers is appropriately facilitated or provided to meet consumer choice/needs.

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 4: Service Delivery

Outcome: Consumers receive services that contribute to their agreed outcomes, and that support their independence, safety and well-being.

Paerewa 5: Te whakawhitinga o ngā ratonga

Standard 5: Transitions within and between services

Palliative care is accessible to all people who need it and it is integrated and coordinated across the person's experience to ensure seamless transition within and between services.

Intent of the standard

People may receive care and services from multiple service providers in many settings to meet their needs as they approach and reach the end of life. A person-centred approach, understanding the person's unique needs and preferences, will ensure potential distress is managed for the person and their family, whānau and carers wherever possible.

The Hospice service has a role throughout the person's experience and will be required to work with a range of other service providers and care settings that provide palliative and end-of-life care. Formal agreements and systems will be essential to support professional collaboration and partnerships.

It is important that any necessary movement and change between services and settings is coordinated, and that the process is safe, smooth, efficient and seamless. Timely referrals and the sharing of information will require efficient and effective communication systems to avoid duplication or gaps in services and care. Managing confidentiality will be essential.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

5.1 The referral and entry criteria are clear, applied consistently, and communicated to the local health providers and wider community.

5.2 The response to a referral is documented and communicated to the person and the referrer.

5.3 There are formal procedures and agreements that support and promote continuity of care within and between services and settings.

5.4 Effective communication systems support integrated and continuous care within and between services.

5.5 The care plan describes actions to support transition and communication across care settings and identifies the most appropriate team member to coordinate the process.

5.6 Referrals are made to other specialists or service providers to meet the needs of the person, their family, whānau and carers.

5.7 The discharge process allows time for services to be put in place and includes a formal handover and follow up to ensure continuity of care and management of risk.

5.8 Access to professional advice and expertise supports other service providers to care for people in the setting of choice.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

Do we have policies and guidelines for admission to the service and transfer/discharge from the service? How is this communicated to other service providers?

Who are the key service providers we work with? Do we have agreements with these providers?

What are the entry criteria?

How do we manage referrals to the service? What are the expected response times?

How do we communicate when a person is declined entry to the service?

How do we manage and support movement and transfer between care settings for people?

How we do we manage potential distress for people during transition?

What communication systems support movement and transfer between care settings? How do we manage confidentiality in this process?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard One: Assessment of needs, Standard Two: Developing the care plan and Standard Three: Providing the care

Policies and procedures

Guidelines to manage and respond to referrals to the service, including expected response times

Documented consent

Referral and entry criteria is available to other service providers, health professionals and the community

Facilitated discharge planning meetings

Formal agreements with other providers of palliative care e.g. MOU

Formal agreements to manage needs assessment for care and funding other services e.g. aged residential care placement

Systems and processes to communicate and share information between settings and services; oral, written and/or electronic

Patient record systems are available 24 hours a day, seven days a week – for hospice staff and other service providers

Documented advance care plans

Coordination model of care

Processes for follow up by the hospice team following a discharge

A system to document and report where care plans cannot be met

Evidence of best practice and the use of validated assessment tools

Admission criteria

Policy and guidelines for managing and responding to referrals; including single point of entry, triage, expected response times and when a person is declined

Access to an urgent assessment is available 24 hours a day, seven days a week

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.3:2008 – Health and Disability Services (Core) Standards – Continuum of service delivery

- **Standard 3.1** – Consumers' entry into services is facilitated in a competent, equitable, timely, and respectful manner, when their need for services has been identified.
- **Standard 3.5** – Consumers' service delivery plans are consumer focused, integrated, and promote continuity of service delivery.
- **Standard 3.8** – Consumers' service delivery plans are evaluated in a comprehensive and timely manner.
- **Standard 3.9** – Consumer support for access or referral to other health and/or disability service providers is appropriately facilitated or provided to meet consumer choice/needs.
- **Standard 3.10** – Consumers experience a planned and coordinated transition, exit, discharge, or transfer from services.

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 2: Organisational Management

Outcome: Consumers receive services that comply with legislation and are managed in a safe, efficient, and effective manner.

Standard 4: Service Delivery

Outcome: Consumers receive services that contribute to their agreed outcomes, and that support their independence, safety and well-being.

Paerewa 6: Te tautoko me te manaaki pāpouri

Standard 6: Grief support and bereavement care

The person at the centre of care, and their family, whānau and carers, have access to grief support and bereavement care services and are provided with information about loss, grief and bereavement.

Intent of the standard

The Hospice service should provide, or offer access to, a range of grief support and bereavement care services for people anticipating or experiencing loss. This may require collaboration and partnerships with a range of other formal providers or community agencies.

Grief, loss and bereavement is individual and unique. It is experienced and expressed emotionally and physically, and it can reflect a spiritual and cultural context, a faith or a religion. The majority of people will integrate loss into their life with the support of family, whānau and friends, and their social, cultural or spiritual community. However, some people will experience a more complicated response to loss requiring further specialist support and care.

Personal and social circumstances may increase a person's risk of experiencing complicated grief. This may lead to problems, or challenges, with engagement in their lives and society in the lead up to and aftermath of a person's death. There may be emotional, spiritual, cultural or psychosocial issues and challenges, or more practical issues such as financial insecurity or risk of homelessness.

Grief support prior to death, as well as during bereavement, may assist in reducing the physical, cultural, spiritual and psychosocial distress or morbidity associated with loss and grief. Early identification of the potential issues and challenges, and timely referral to appropriate support and expertise can assist the person, family and whānau and carers, with preparing for and responding to a death.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

6.1 Education about cultural, spiritual and emotional expression of loss, grief and bereavement is provided to staff, volunteers and other service providers.

6.2 Culturally and spiritually appropriate information and resources about loss, grief and bereavement services are provided to people, families, whānau and carers before and after the death.

6.3 The person, and their family, whānau and carers, have access to grief support and bereavement care, including specialist grief support services.

6.4 There are processes to identify people at risk of, or experiencing, a complicated response to their loss.

6.5 The needs of the person's family,whānau and carers are reassessed as the person's condition changes and following death.

6.6 The family, whānau and carers are provided with information on the signs and symptoms of approaching death and the steps required following death.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

What grief support and bereavement care services do we provide?

Who is providing the services?

Are the clinical team members specifically trained and/or qualified?

What resources do we provide and how do we assess their effectiveness?

How do we prepare staff and volunteers to identify signs of complicated grief?

How do we assess levels of risk associated with loss and grief for people?

How do we access other specialist advice for loss, grief and bereavement?

Do we provide education for other service providers and/or the community?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard Four: Supporting and caring for the family, whānau and carers

Policies and procedures

Documented consent

Grief and bereavement care service provided by a qualified and skilled team

Bereavement volunteer services

Bereavement groups

Access to external grief and bereavement service when not provided by the hospice

Documented assessment and care plan for bereavement care and support

Use of validated tools to assess level of risk for complicated grief

Education and training for staff and volunteers

Resources and information for staff and volunteers available

Support for staff and volunteers e.g. debriefs, access to Employee Assistance Programme

Referral process to access specialist grief support services and counselling for specific needs e.g. complicated grief, children and adolescents, mental health, counselling services, Kaupapa Māori services

Resources and information for people and their family,whānau and carers e.g. verbal, written and digital

Links and partnerships with community organisations that support people experiencing loss, grief and bereavement

Biography service

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.3:2008 – Health and Disability Services (Core) Standards – Continuum of service delivery

- **Standard 3.2** – Where referral/entry to the service is declined, the immediate risk to the consumer and/or their family/whānau is managed by the organisation, where appropriate.
- **Standard 3.3** – Consumers receive timely, competent, and appropriate services in order to meet their assessed needs and desired outcome/goals.
- **Standard 3.4** – Consumers' needs, support requirements, and preferences are gathered and recorded in a timely manner.

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 4: Service Delivery

Outcome: Consumers receive services that contribute to their agreed outcomes, and that support their independence, safety and well-being.

Paerewa 7: Te ahurea o te tari

Standard 7: Culture of the organisation

The Hospice service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative and end-of-life care.

Intent of the standard

Hospice services are expected to be leaders in the delivery of high quality palliative care, providing services to people who may need a higher level of care and support as they approach and reach the end of their life. For some Hospice services, formal agreements with other services and providers will be necessary to meet this expectation.

The principles of the *Treaty of Waitangi* (1840) are applied to improve access, achieve equity and improve palliative care outcomes.

The Hospice service supports the delivery of compassionate person-centred palliative and end-of-life care and provides access to services that respects and recognises the unique and individual needs of all people.

A governance and management structure will support the staff to provide a respected service to the community and for all those people using, or interacting, with the Hospice service. A clearly stated vision, philosophy and values will support the organisational culture for staff and volunteers.

A strategic plan will provide clear direction for sustainable service delivery and identify the necessary resources, funding and organisational change to meet the changing needs of the community served.

Hospice services should seek opportunities to influence community development and the delivery of care at the end of life in other settings through professional networking, collaboration, partnerships, advocacy and a public health approach.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

7.1 The philosophy, values and goals of the Hospice service are embedded in clinical and organisational guidelines, policies and procedures.

7.2 The values and culture of the Hospice service explicitly support person-centred care.

7.3 The governance, leadership and clinical structure supports staff and volunteers and the delivery of quality care.

7.4 There is an understanding of the palliative care needs of the community which informs the services provided.

7.5 The care setting promotes a safe environment which supports people, and their family, whānau and carers, as they approach the end of life.

7.6 The community is aware and supports the increasing need for palliative and end-of-life care services.

7.7 Partnership with Māori at operational and governance level supports the provision of services that meet the needs of Māori.

7.8 The cultural competence of staff and volunteers is developed through access to Treaty of Waitangi training and support.

7.9 Access to support and training to enhance the awareness of staff and volunteers of culturally appropriate care to meet the needs of Māori and the diverse population they serve.

7.10 A comprehensive education programme is available to other providers of palliative and end-of-life care.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

What is our governance and management structure?

What is our philosophy?

Do we have a vision and values that support a person-centred approach? How do we know this is understood and practised by all staff and volunteers?

Are Māori represented at all levels of the service?

How do we plan and meet the needs of all people accessing the service?

How do we support the work of the clinical team?

How do we promote a safe environment for people and their family, whānau and carers?

How do we engage and work with the community and other service providers?

How is our education and training programme planned, delivered and evaluated?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard Eight: Quality improvement and research and Standard Nine: Staff qualifications and training

Strategy

Codes

Contract compliance

Policies and procedures

Human resources policies and procedures

Continuous quality improvement programme

Organisational statements – strategic plan with articulated vision, mission and values

Public information on the service and what it provides e.g. written materials and website

The principles of the Treaty of Waitangi are embedded in the service

Compliance with legislation as required e.g. health and safety, employment practice, financial practice and reporting

Personnel records maintained

Governance and leadership structure

A person-centred philosophy is integrated across all teams and services

Staff support programme e.g. staff meetings, supervision, debriefing

Formal reporting and communication process – internal and external

Community awareness and communications programme

Community and consumer engagement

A fund raising programme based on best practice standards and guidelines

Māori Health Plan

Pacific Health Plan

Appointment of specific cultural advisors e.g. Māori Advisor and Pacific Advisor

Agreements and formal partnerships with external service providers e.g. aged residential care, primary health providers, Māori health providers

Partnership and agreements with local Māori

Māori are represented or accessed at governance level

Partnership and agreements with cultural and spiritual groups

Treaty of Waitangi workshops

Delivery of national education programmes

Cultural and spiritual education and training for all staff and volunteers

Engagement and formal links with the community

Environmental survey and needs analysis

National, regional and local data and demographics

Patient and family and whānau satisfaction survey

Staff and volunteer satisfaction survey

Management of complaints

Public health model of engagement

Public awareness and resources

Benchmarking with other hospices

Engagement and membership of local, regional and national networks and projects

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.2:2008 Health and Disability Services (Core) Standards – Organisational management

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 2: Organisational Management

Outcome: Consumers receive services that comply with legislation and are managed in a safe, efficient, and effective manner.

Standard 3: Human Resources

Outcome: Consumers receive safe, efficient, and effective services from an organisation that is a good employer and follows human resources practices.

Paerewa 8: Te whakapakari kounga me te rangahau

Standard 8: Quality improvement and research

Hospice services are engaged in quality improvement and research to improve service provision and the development of palliative and end-of-life care.

Intent of the standard

Continuous quality improvement and research is essential to develop, support and improve the delivery of safe, quality palliative and end-of-life services; locally, regionally and nationally.

The Hospice service should promote and embed a robust cycle of continuous quality improvement and an organisational culture of quality activity and risk management. This should apply to all staff and across all the services offered and provided. People using, or interacting with, the Hospice service are given the opportunity to contribute to the way services are delivered. Where relevant, this should involve, and contribute to, the services provided by other service providers.

It is expected that all Hospice services comply with the necessary legislative requirements for the level and type of services provided.

Research provides evidence to improve and increase knowledge and inform clinical practice. The level of engagement or participation in conducting research may vary with the capacity and capability of the Hospice service and the clinical staff.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

8.1 The quality programme supports the strategic and annual planning process which is implemented, evaluated and regularly reviewed.

8.2 A system of clinical governance supports the delivery of clinical services and care.

8.3 Opportunities for improvement are identified, prioritised, implemented and evaluated using a continuous improvement process.

8.4 Data and information are collected, analysed and used to identify the effectiveness of service delivery and reported to governance, funding agencies and stakeholders.

8.5 Systems and processes are reviewed and improved to support care and service delivery.

8.6 Opportunities are sought and developed to benchmark with other services.

8.7 Staff receive training and are supported to use tools and models of quality improvement.

8.8 Support is available for other service providers providing care for people at the end of life to improve the quality of that care.

8.9 Feedback from the community, users of the Hospice service and stakeholders is incorporated into quality improvements.

8.10 Staff lead, participate in, and use research to inform practice and care.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

How do we ensure compliance with legislation?

How do we ensure that quality improvement is promoted and embedded across the service?

How do we maintain and provide safe services?

Are we using the best available evidence to support clinical practice?

What data do we collect and/or use to plan services?

How do we ensure a patient-centred approach to care and services?

How are we measuring patient and family and whānau outcomes?

Do we use opportunities to benchmark with other services?

How do we engage with consumers on service improvement?

Are we involved in any research and how do we use it in practice?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard Seven: Culture of the organisation and Standard Nine: Staff qualification and training

Certification and accreditation status current as required

Monitoring of contract requirements

Application of legislation

An evidence-based approach to service development and quality improvement

Continuous quality improvement programme and planning

Identified quality leadership e.g. manager/coordinator

All staff aware and involved in the quality programme – included in staff meetings

Process for reviewing policies and procedures

Coordination of the quality programme

Collection and application of (local, regional and national) data and information e.g. ethnicity, age, place of death, uptake of the service

Regular internal audits – service and clinical

Clinical outcome measurement tools

Benchmarking

Risk management process

Reporting and management of incidents

Management of complaints process

Management of adverse events and corrective action process

Education and training on quality for staff and volunteers – included in orientation programme

Education and training programme on palliative and end-of-life care

Participation in the delivery of regional and national palliative and end-of-life care education programmes

Patient and family and whānau survey

Staff satisfaction survey

Membership of quality networks

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.1:2008 – Health and Disability Services (Core) Standards – Consumers rights

NZS 8134.1.2:2008 Health and Disability Services (Core) Standards – Organisational management

- **Standard 2.3** – The organisation has an established, documented, and maintained quality and risk management system that reflects continuous quality improvement principles.
- **Standard 2.4** – All adverse, unplanned, or untoward events are systematically recorded by the service and reported to affected consumers and where appropriate their family/whānau of choice in an open manner.

NZS 8158:2012
Home and Community Support Sector Standard

Standard 1: Consumer Rights

Outcome: Every consumer's values, dignity, and culture are recognised and supported, their choices respected, and their rights upheld.

Standard 2: Organisational Management

Outcome: Consumers receive services that comply with legislation and are managed in a safe, efficient, and effective manner.

Paerewa 9: Ngā tohu me ngā mahi whakangungu a ngā kaimahi

Standard 9: Staff qualifications and training

Staff and volunteers are skilled, competent, qualified, and engaged in continuing professional development appropriate to their role and the capability of the Hospice service.

Intent of the standard

A Hospice service is expected to employ, or provide access to, clinical staff that have current and recognised qualifications or credentialing in palliative care to provide safe, competent, quality palliative and end-of-care to meet the needs of the people using the service.

Staff require ongoing support to maintain their professional development and to perform and meet the demands of their role. This should apply to all staff in clinical, non-clinical and management support roles. The support should be focused and structured to meet current and future needs.

Volunteer services support the service and the staff in many important roles. The volunteers should be supported to fulfil these roles safely and competently.

Standard Elements

To meet this standard, the Hospice service is expected to ensure:

9.1 Employment practices support the recruitment of appropriately qualified, skilled and experienced staff and volunteers to meet the needs of people using the service.

9.2 New staff and volunteers are provided with appropriate orientation to palliative care, the service and their role.

9.3 Staff are supported to gain, and maintain, recognised qualifications, competency, skills and/or experience for their role.

9.4 Staff have a formal and documented assessment of their education and training needs to support their continuing professional development.

9.5 Staff and volunteers are supported to maintain self-care, resilience and engagement.

9.6 Volunteers are recognised, trained, supported and managed in accordance with volunteer guidelines.

Prompt questions

These questions provide a focus for the team to discuss and ask themselves how they are meeting this Standard.

How do we evaluate/measure that the intent of this standard is being met?

Do we have policies and procedures to support education and training?

What is our recruitment process for staff and volunteers?

Do we provide a formal orientation programme for staff and volunteers?

How do we support professional development for staff?

How are staff encouraged and supported to gain qualifications in palliative care?

How many clinical staff members have a recognised postgraduate qualification in palliative care?
How is this recorded?

How do we maintain a sustainable workforce?
Do we have a succession planning strategy?

How do we promote resilience amongst staff and volunteers?

How do we support and train volunteers?

Guidance

The following list may assist and guide services to address the elements of this Standard.

Refer to Standard Seven: Culture of the organisation and Standard Eight: Quality improvement and research

Organisational statement and commitment to education and training for staff and volunteers

Allocated funding for education and training

Policies and procedures

The skill mix and ratio of qualified clinical staff is appropriate to the level of service provided

Orientation programme for new staff and volunteers

Staff have the appropriate qualifications and credentials for their role

Record of professional practice requisites

Performance review and appraisal programme

Professional development programme

Formal relationship with educations institutions

Records of education and training sessions delivered

Attendance records for education and training

Record of professional and clinical qualifications and credentials

Access to resources and information for staff and volunteers

Wellness programmes

Support processes to promote self care and resilience for staff and volunteers e.g. supervision, peer support, mentoring, debriefing, access to external support

Mapping

This mapping has been developed to assist services to identify alignment and to avoid duplication.

NZS 8134:2008
Health and Disability Services Standards

NZS 8134.1.2:2008 Health and Disability Services (Core) Standards – Organisational management

- **Standard 2.7** – Human resource management processes are conducted in accordance with good employment practice and meets the requirements of legislation.
- **Standard 2.8** – Consumers receive timely, appropriate and safe service from suitably qualified/skilled and/or experienced service providers.

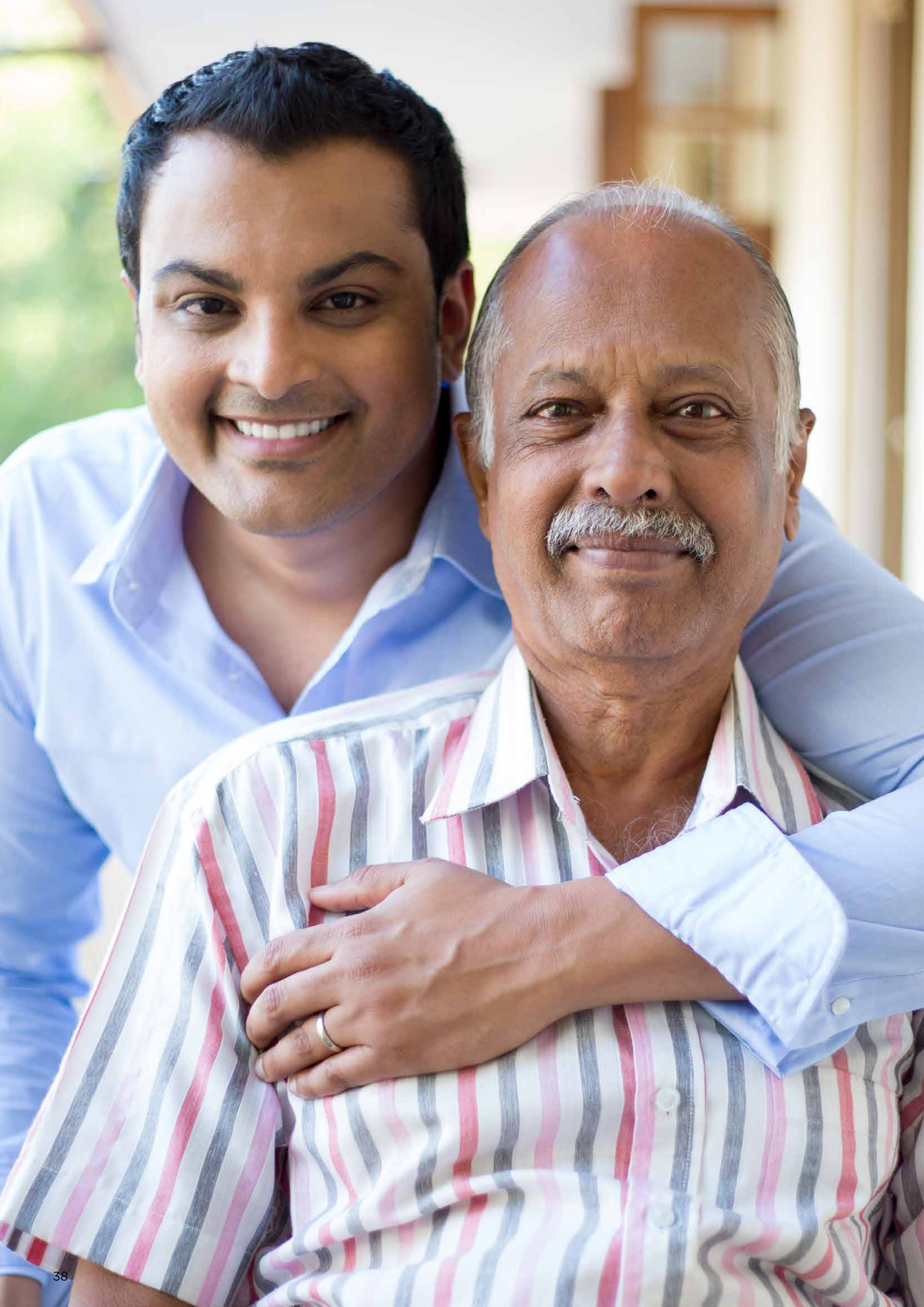
NZS 8158:2012
Home and Community Support Sector Standard

Standard 2: Organisational Management

Outcome: Consumers receive services that comply with legislation and are managed in a safe, efficient, and effective manner.

Standard 3: Human Resources

Outcome: Consumers receive safe, efficient, and effective services from an organisation that is a good employer and follows human resource practices.



He papakupu

Glossary

This glossary is provided to assist with interpretation and understanding the Standards.

It has been adapted from *The New Zealand Palliative Care Glossary* (Ministry of Health, 2015).

For the purpose of this document, and to provide a working context, key terms have been selected and some terms have been modified in the interest of space. We recommend readers refer to the original document for a fuller description of terms, background to the decisions and use of terms, and some specific Māori language and description relevant to palliative care.

* Extra terms (working definitions) have been added that are specific to the Standards and these are identified by an asterisk.

This is not an exhaustive list and we recommend further reading as required.

Advance Care Plan: the desired outcome of the advance care planning process. It is an articulation of wishes, preferences, values and goals relevant to all current and future care.

An advance care plan may itself be regarded as an advance directive and should be consistent with, and considered in conjunction with, any advance directive that exists.

Advance Care Planning: a process of discussion and shared planning for future health care. Focused on the individual, it involves the person and the health care professionals responsible for their care. It may involve the person's family and whānau and/or carers if that is the person's wish.

Advance care planning provides individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

***Advance Directive:** is a statement signed by a person setting out in advance the treatment they want or do not want in the event of becoming unwell in the future. An advance directive can be a good way to gain more control over the treatment and care given if a person experiences an episode of mental illness that leaves them unable to decide or communicate their preferences at the time. The directive is not legally binding, but rather provides information for consideration by the attending clinician/s.

***Benchmarking:** refers to formal/informal methods that support services to create a picture of service and care delivery in order to observe, monitor and compare trends and changes within an individual service across time and/or across other services.

Bereavement: the period of grief and mourning after a death. It is part of the normal process of reacting to a loss. Grief may be experienced as a mental, physical, social or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness and despair. Physical reactions can include sleeping problems, changes in appetite, physical problems or illness.

***Care Plan:** is a dynamic document (written or electronic) that is developed in negotiation with the person. It captures, outlines and guides the planned goals and interventions to meet the needs identified by assessment.

***Care Setting:** is the location where care is provided, including the person's home, aged residential care facility, hospice and hospital.

***Carer:** is the person who provides care, support and assistance to another person. They may be the spouse, partner, parent, child, guardian or friend or a volunteer provided by a service. A carer is generally not paid.

Chronic Condition: a biological or physical condition where the natural evolution of the condition can significantly impact on a person's overall quality of life, including an irreversible inability to perform basic physical and social functions. Serious and persistent chronic conditions are multidimensional, interdependent, complex and ongoing. Chronic conditions are characterised by persistent and recurring health consequences lasting for three months or more.

***Clinical Outcome Measurement:** captures a change in a person's health status as a consequence of health care or intervention. The focus is on the person and their family and whānau, and the outcomes are measured using systems and tools that are validated for the palliative population. These tools can be used for both individual assessment and patient management but can also contribute to a body of evidence to measure the impact of palliative care.

***Community:** can refer to a geographic area and the people living within this area or to a group of people who share a common profile and attributes.

Death: the cessation of all vital functions of the body, including the heartbeat, breathing and brain activity (including the brain stem).

Dying: a person is considered to be dying when they are in the process of passing from life to death.
See also Last Days of Life.

End of Life: is that period of time prior to death; the duration can never be precisely defined in advance.

End-of-Life Care: is the care guided by the person's needs and goals and is the responsibility of all who work within the health sector.

Enduring Power of Attorney: an authority given by a person, while they are competent, to allow another person to act for the welfare of the person only when the person becomes mentally incompetent.

***Evidence:** is the integration of the best available validated research, clinical expertise and a person's values.

Family: those closest to the person in knowledge, care and affection. The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets).

***Health Literacy:** is a person's capacity to access, interpret and use information and health services to make effective decisions for health and wellbeing.

Holistic care: is comprehensive, total care that considers the physical, emotional, social, economic, and spiritual needs of the person, their response to the health condition, and the effect of the condition on their ability to meet self-care needs. The principles of palliative care are framed around holistic care and the interdependent physical, social, emotional, cultural and spiritual aspects.

Hospice: is a philosophy of care; not just a building.

The goal of hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high quality palliative care. Hospice staff provide care for the whole person, not just their physical needs but also their emotional, cultural, spiritual, and social needs. They also care for families, whānau and friends, both before and after a death. Irrespective of where a hospice service is provided, this philosophy of care does not change.

Interdisciplinary Team: a group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members collaborate to solve problems too complex to be solved by one discipline alone, or several disciplines in sequence. Membership varies depending on the services required to identify and address the expectations and needs of the person, caregiver and family. A palliative care interdisciplinary team typically includes one or more doctors, nurses, social workers, counsellors, spiritual advisers, pharmacists, and personal care workers. Other disciplines will be part of the team as resources permit.

Kaupapa Māori: Māori approach, Māori topic, Māori customary practice, Māori institution, Māori agenda, Māori principles, Māori ideology – a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society.

Last Days of Life: is the period when a person is dying. It is the period of time when death is imminent and may be measured in hours or days.
See also End of Life

Life-Limiting Condition: a condition for which there is no reasonable hope of cure and from which the person is expected to die. Some of these conditions cause progressive deterioration rendering the person increasingly dependent on family and carers.

See also Life-threatening Condition and Terminal Condition.

Life-Threatening Condition: a condition for which curative treatment may be feasible but can fail.

A life-threatening condition is usually of short duration with an acute or unexpected onset and may or may not occur in the context of a pre-existing life-limiting condition.

See also Life-limiting Condition and Terminal Condition.

Long-Term Condition: an ongoing, long-term or recurring condition that may have a significant impact on a person's life.

See also Chronic Condition.

***Other Service Providers:** refers to a range of health and community care providers, professionals, agencies and services that provide palliative care services and/or work in partnership with hospices to meet the identified needs of the person and their family and whānau.

Multidisciplinary team: a team that consists of a mix of health care disciplines. Team members share common goals, collaborate and work together in planning and delivery of care. Members of a multidisciplinary team might include GPs, surgeons, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, counsellors, occupational therapists, physiotherapists, dieticians, volunteers, pharmacists or care assistants.

Palliation: is the alleviation of symptoms when the underlying medical condition or pathological process cannot be cured. The term is used widely in health care to refer to treatments or interventions (including surgical) that are focused on alleviation of pain or other symptoms and is not necessarily limited to care provided for life-limiting and life-threatening conditions. The goal of palliation is to help a person feel more comfortable, and to improve quality of life. Palliation is a key goal of care for both end of life and palliative care.

Palliative Care: is care for people of all ages with a life-limiting or life-threatening condition which 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, whānau, and other caregivers where needed, through the illness and after death.

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life. It should be available wherever the person is. It should be provided by all health care professionals, supported where necessary, by specialist palliative care services.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. This includes but is not limited to; Māori, children and young people.

Palliative Care Approach: an approach to care which embraces the definition of palliative care. It incorporates a positive and open attitude toward death and dying by all service providers working with the person, their family and whānau, and respects the wishes of the person in relation to their treatment and care.

Palliative Care System: comprises specialist palliative care services, primary palliative care providers and the other factors that enable them to deliver palliative care, such as communication and coordination between providers. It is not simply the existence of primary palliative care providers and specialist palliative care services that comprises the palliative care system; it is the links between that tie together 'a system'. An interdisciplinary team approach to palliative care is one example of how such links can be developed and maintained.

Person (or Patient): the primary recipient of care. In the practice of palliative care, the person together with their family and whānau and carers are the focus of care. The preferred term in New Zealand is person rather than patient.

***Person-centred:** is a concept that respects the cultural needs, preferences, values, beliefs, relationships and life experience of each person. It involves a mutual relationship between the person and the team and places the person in the centre of all planning for individualised care and services. Family and whānau should be considered, and involved where possible, in this process.

***Qualified:** is where a person (health professional) has completed specific and recognised training/accreditation in palliative care/medicine.

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

Specialist palliative care may be provided by hospice or hospital-based palliative care services where people have access to, at the very least, medical and nursing palliative care specialists.

Specialist palliative care is delivered in two key ways:

- Directly – to provide direct management and support of the person, and their family and whānau, where more complex palliative care needs exceed the resources of the primary provider. Specialist palliative care involvement with any person and the family and 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, social or spiritual.
- Indirectly – to provide advice, support, education and training for other health professionals and volunteers to support the primary provision of palliative care.

Specialist Palliative Care Service: a team or organisation whose core work focuses on delivering palliative care, for example, a hospice or hospital palliative care team supported by education, quality improvement and research programmes.

***Standards:** are a shared set of agreed and achievable outcomes and expectations, against which performance is assessed and measured.

Supportive Care (in the context of cancer): care which aims to improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care. Supportive care and rehabilitation services include the essential services required to meet a person's physical, social, cultural, emotional, nutritional, informational, psychological, spiritual and practical needs throughout their experience with cancer.

Te Ara Whakapiri: the path of closeness and unity.

The Māori name for the principles and guidance for the last days of life. This guidance represents the recommended approach to caring for all people in New Zealand across all sectors and settings who have a life-limiting illness and are in their last days of life.

Te Whare Tapa Whā: a Māori model of health developed by Professor Mason Durie, derived from a Māori world view. The health of a person is likened to the four walls or cornerstones of a house. All four are essential for the house to stand strong, as they are essential for the holistic health of a person. The cornerstones are the physical health of the body; social wellbeing derived from whānau and community connectedness; mental health relating to the well spring of thoughts and feelings of a person about themselves and the wider world; and a person's spiritual health, the spiritual power and dignity within a person along with their fundamental belief system.

- Te Taha Tinana – physical health
- Te Taha Hinengaro – psychological health
- Te Taha Wairua – spiritual health
- Te Taha Whānau – family health.

Terminal Condition: a progressive condition that has no cure and that can be reasonably expected to cause the death of a person within a foreseeable future. The definition is inclusive of both malignant and non-malignant conditions and ageing.

See also Life-limiting Condition and Life-threatening Condition.

***Tikanga:** Māori practice and behaviour including customs and rites. Tikanga encompasses, among other things, karakia, tapu, rāhui, rangatiratanga, kotahitanga, wairuatanga, manaakitanga.

Whānau: extended family, family group, a familiar term of address to a number of people. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members.

Whānau Ora: the concept of supporting Māori families to achieve their maximum health and wellbeing.

He rārangi korero

References

Durie, M. (1998). *Tirohanga Māori: Māori health perspectives.*
Auckland: Oxford University Press.

Hospice New Zealand. (2012). *Standards for palliative care. Quality review programme and guide. (3rd edition).* Wellington: Author.
Available from: **www.hospice.org.nz**

Ministry of Health. (2013). *Resource and capability framework for integrated adult palliative care services in New Zealand.* Wellington: Author.
Available from: **www.health.govt.nz/system/files/documents/publications/resource-capability-framework-adult-palliative-care-services-v2.pdf**

Ministry of Health. (2014). *He Korowai Oranga – Māori health strategy.*
Wellington: Author.
Available from: **www.health.govt.nz/publication/guide-he-korowai-oranga-maori-health-strategy**

Ministry of Health. (2015). *New Zealand palliative care glossary.* Wellington: Author.
Available from: **www.health.govt.nz/publication/new-zealand-palliative-care-glossary**

Ministry of Health. (2017a). *Palliative care action plan.* Wellington: Author.
Available from: **www.health.govt.nz/publication/palliative-care-action-plan**

Ministry of Health. (2017b). *Te Ara Whakapiri: Principles and guidance for the last days of Life. (2nd edition).* Wellington: Author.
Available from: **www.health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life**

Ministry of Health. (2017c). *Te Ara Whakapiri Toolkit: Care in the last days of life.*
Wellington: Author.
Available from: **www.health.govt.nz/system/files/documents/publications/te-ara-whakapiri-toolkit-apr17.pdf**

Palliative Care Australia. (2018). *National palliative care standards. (5th edition).*
Canberra: Author.
Available from: **www.palliativecare.org.au/standards**

Standards New Zealand. (2008). *Health and disability services standards.*
NZS 8134.1.2008. Wellington: Author.

Standards New Zealand. (2012). *Home and community support sector standards.*
NZS 8158:2012. Wellington: Author.

Treaty of Waitangi. (1840).
Available from: **www.mch.govt.nz/treatyofwaitangi**

World Health Organisation. (2018). *Definition of palliative care.*
Available from: **www.who.int/cancer/palliative/definition/en/**

Ngā ture o Aotearoa

New Zealand Legislation

Employment Relations Act. (2000). (Amended 2018)
Available from: **www.legislation.govt.nz/act/public/2000/0024/latest/versions.aspx**

Health Practitioners Competence Assurance Act. (2003). (Reprinted 2017).
Available from: **www.legislation.govt.nz/act/public/2003/0048/latest/DLM203312.html**

Health and Disability Commissioner Act. (1994). (Reprinted 2017).
Available from: **www.legislation.govt.nz/act/public/1994/0088/latest/whole.html**

Health and Disability Services (Safety) Act. (2001). (Reprinted 2017).
Available from: **www.legislation.govt.nz/act/public/2001/0093/latest/DLM119975.html**

Health and Safety at Work Act. (2015). (Reprinted 2018).
Available from: **www.legislation.govt.nz/act/public/2015/0070/55.0/DLM5976660.html**

Human Rights Act. (1993). (Reprinted 2018).
Available from: **www.legislation.govt.nz/act/public/1993/0082/60.0/DLM304212.html**

Medicines Act. (1981). (Reprinted 2018).
Available from: **www.legislation.govt.nz/act/public/1981/0118/75.0/DLM53790.html**

Medicines Regulations Act. (1981). (Reprinted 2018).
Available from: **www.legislation.govt.nz/regulation/public/1984/0143/latest/DLM95668.html**

Privacy Act. (1993). (Reprinted 2019).
Available from: **www.legislation.govt.nz/act/public/1993/0028/latest/DLM296639.html**

Protection of Personal and Property Rights Act. (1988). (Reprinted 2018).
Available from: **www.legislation.govt.nz/act/public/1988/0004/latest/DLM126528.html**

Protection of Personal and Property Rights Act. (Enduring Powers of Attorney Forms and Prescribed Information). Amendment Regulations (2017).
Available from: **www.legislation.govt.nz/regulation/public/2017/0044/latest/DLM7144401.html**

Treaty of Waitangi Act. (1975). (Reprinted 2018).
Available from: **www.legislation.govt.nz/act/public/1975/0114/107.0/DLM435368.html**

Ngā tikanga matatika o Aotearoa

New Zealand Codes

Code of Health and Disability Services Consumers' Rights. (1996).
Available from: **www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/**

Health Information Privacy Code. (1994).
Available from: **www.privacy.org.nz/the-privacy-act-and-codes/codes-of-practice/health-information-privacy-code-1994/**

Code of Practice for Health Workers.
Available from: **www.health.govt.nz/our-work/who-code-nz/code-practice-health-workers**

Ngā rautaki o Aotearoa

New Zealand Strategies

Ministry of Health. (2001). *The New Zealand Palliative Care Strategy.* Wellington: Author.
Available from: **www.health.govt.nz/publication/new-zealand-palliative-care-strategy**

Ministry of Health. (2014). *He Korowai Oranga: Māori Health Strategy.* Wellington: Author.
Available from: **www.health.govt.nz/publication/guide-he-korowai-oranga-maori-health-strategy**

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

Ministry of Health. (2016). *The New Zealand Health Strategy and Roadmap.* Wellington: Author.
Available from: **www.health.govt.nz/publication/new-zealand-health-strategy-2016**

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

Ngā rauemi whaitake

Useful Resources

General resources

Health Quality and Safety Commission. (2017). *Clinical governance. Guidance for health and disability providers*. Wellington: Author.
Available from: **www.hqsc.govt.nz/assets/Capability-Leadership/PR/HQS-ClinicalGovernance.pdf**

Health Quality Improvement Partnership. (2015). *A guide to quality improvement methods*. UK: Author.
Available from: **www.hqip.org.uk/resource/guide-to-quality-improvement-methods/**

MacLeod, R. & Macfarlane, S. (2019). *The palliative care handbook. (New Zealand 9th edition). Guidelines for clinical management and symptom control, featuring extensive support for advanced dementia*. Wellington: Hospice New Zealand.
Available from: **http://www.hospice.org.nz/resources/palliative-care-handbook**

MacLeod, R.D. & Van den Block, L. (Editors). (2019). *Textbook of palliative care*. Springer, Cham.
Available from: **www.doi.org/10.1007/978-3-319-31738-0** ISBN 978-3-319-31738-0

Ministry of Health. (2015). *Health literacy review: A guide*. Wellington: Author.
Available from: **www.health.govt.nz/publication/health-literacy-review-guide**

Ministry of Health. (2017). *Review of adult palliative care services in New Zealand*. Wellington: Author.
Available from: **www.health.govt.nz/publication/review-adult-palliative-care-services-new-zealand**

The National Institute for Care and Excellence (NICE), UK. (2017). *Care of dying adults in the last days of life*.
Available from: **www.nice.org.uk/guidance/qs144**

Resources for specific population groups

(Also refer to list of websites)

Schwass, M. (Editor). (2006). Last words. *Approaches to death in New Zealand cultures and faiths*. New Zealand: Bridget Williams Books.
Available from: **www.bwb.co.nz/books/last-words ISBN: ISBN: 9781877242342**

Māori people

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

Ministry of Health. (2014). *Tikanga ā-Rongoā – Ko tēnei te tuhinga reo Māori*. Wellington: Author.
Available from: **www.health.govt.nz/publication/tikanga-rongoa**

Ministry of Health. (2014). *Palliative care and Māori from a health literacy perspective*. Wellington: Author.
Available from: **www.health.govt.nz/publication/palliative-care-and-maori-health-literacy-perspective**

People from Pacific Island nations

Ministry of Health. (2014). *'Ala Mo'ui: Pathways to Pacific health and wellbeing 2014–2018*. Wellington: Author.
Available from: **www.health.govt.nz/publication/ala-moui-pathways-pacific-health-and-wellbeing-2014-2018**

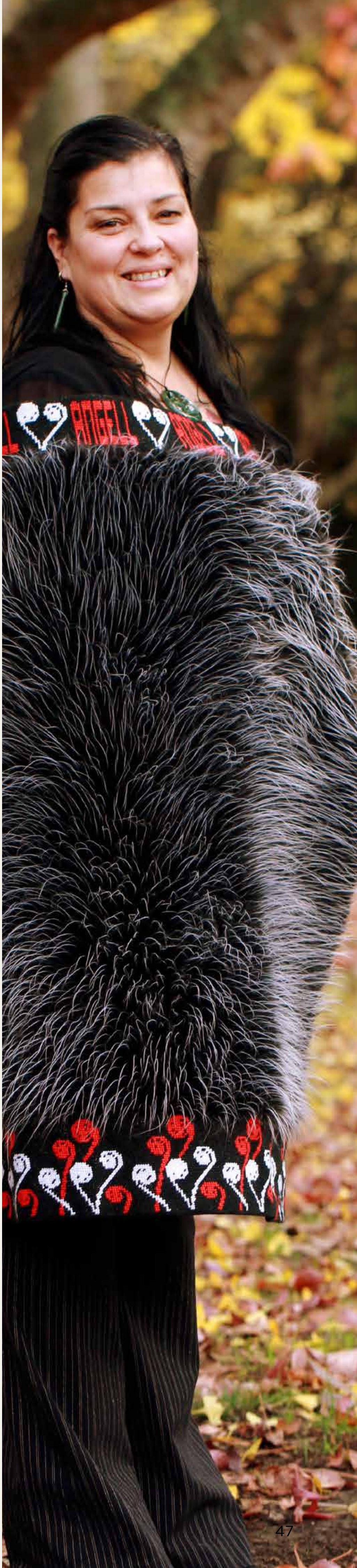
People with a culturally and linguistically diverse background

Palliative Care Australia. (2015). *Palliative care and culturally and linguistically diverse communities*. Canberra: Author.
Available from: **www.palliativecare.org.au/wp-content/uploads/2015/08/PCA-Culturally-and-Linguistically-Diverse-Communities-and-Palliative-Care-Position-Statement.pdf**

People living with a chronic or long-term condition

Ministry of Health. (2007). *Meeting the needs of people with chronic conditions*. Wellington: Author.
Available from: **www.health.govt.nz/publication/meeting-needs-people-chronic-conditions-0**

Ministry of Health. (2014). *Self-management support for people with long term conditions*. Wellington: Author.
Available from: **www.health.govt.nz/system/files/documents/publications/self-management-support-people-with-long-term-conditions-feb16_0.pdf**



People who live in an aged residential care facility

Palliative Care Australia, et al. (2017). *Principles for palliative care and end-of-life care in residential aged care*. Canberra: Author.
Available from: **www.palliativecare.org.au/wp-content/uploads/dlm_uploads/2017/05/PCA018_Guiding-Principles-for-PC-Aged-Care_W03-002.pdf**

People who are homeless

Klop, H.T. (2018). Palliative care for homeless people: A systematic review of the concerns, care needs and preferences, and the barriers and facilitators for providing palliative care. *BioMed Central Palliative Care, 17*: 67. doi: 10.1186/s12904-018-0320-6
Available from: **www.ncbi.nlm.nih.gov/pmc/articles/PMC5914070/**

People living with dementia

Dementia Australia and Palliative Care Australia. (2018). *Policy statement – palliative care and dementia*. Canberra: Palliative Care Australia.
Available from: **www.dementia.org.au/files/documents/Dementia-Policy-Statement-2018.pdf**

Ministry of Health. (2014). *Improving the lives of people with dementia*. Wellington: Author.
Available from: **www.health.govt.nz/publication/improving-lives-people-dementia**

Children and adolescents with a life-limiting condition

National Paediatric Palliative Care Clinical Network. *National paediatric palliative care clinical guidelines*.
Available from: **www.starship.org.nz/for-health-professionals/national-paediatric-palliative-care-clinical-guidelines/#All**

People who are lesbian, gay, bisexual, transgender, queer or questioning, and intersex (LGBTQI+)

Rainbow Tick. (2013). *Some common terms used in New Zealand*.
Available from: **www.rainbowtick.co.nz/files/2013/11/Some-Common-Terms-used-in-New-Zealand.pdf**

La Trobe University. (2016). *The Rainbow Tick guide to LGBTI-inclusive practice*. Prepared by Pamela Kennedy. La Trobe University. Melbourne: Author.
Available from: **www.qip.com.au/standards/rainbow-tick-standards/**

Palliative Care Australia. (2015). *Palliative care for lesbian, gay, bisexual, transgender people and people with intersex characteristics (LGBTI)*.
Canberra: Author.
Available from: **www.palliativecare.org.au/wp-content/uploads/2015/04/LGBTI-Position-Statement.pdf**

Ngā paetukutuku

Websites

Hospice New Zealand
www.hospice.org.nz/

Alzheimers New Zealand
www.alzheimers.org.nz/

eCALD
www.ecald.com/

Care Search Palliative Care Knowledge Network
www.caresearch.com.au/Caresearch/Default.aspx

Dementia New Zealand
www.dementia.nz/

HealthCERT
www.health.govt.nz/our-work/regulation-health-and-disability-system/certification-health-care-services

Health and Disability Commissioner
www.hdc.org.nz/

Health Literacy New Zealand
www.healthliteracy.co.nz/page/about-health-literacy/

Health Quality & Safety Commission New Zealand
www.hqsc.govt.nz/

Hospice UK
www.hospiceuk.org/

IHC New Zealand
www.ihc.org.nz/

Māori Health
www.health.govt.nz/our-work/populations/maori-health

Ministry of Health
www.health.govt.nz/

Ministry of Health – Populations
www.health.govt.nz/our-work/populations

Ministry for Pacific Peoples
www.mpp.govt.nz/pacific-people-in-nz

Ministry of Social Development's Senior Services
www.msd.govt.nz/what-we-can-do/seniorcitizens/index.html

National Institute for Clinical Excellence (NICE)
www.nice.org.uk/guidance

Office for Disability Issues
www.odi.govt.nz/

Paediatric Palliative Care Clinical Network
www.starship.org.nz/for-health-professionals/new-zealand-child-and-youth-clinical-networks/paediatric-palliative-care-clinical-network/

Palliative Care Australia
www.palliativecare.org.au/

Palliative and End of Life Care: A Blueprint for Improvement
www.aci.health.nsw.gov.au/palliative-care-blueprint

Rainbow Tick
www.rainbowtick.co.nz/resources/

Standards New Zealand
www.standards.govt.nz/

Te whakamahere tiaki i mua i te wā taumaha: Advance Care Planning
www.hqsc.govt.nz/our-programmes/advance-care-planning/

World Health Organisation
www.who.int/

Living Every Moment
hospice
New Zealand

50 Manners Street, PO Box 11557, Wellington 6142
T: 04 381 0266 | www.hospice.org.nz