Living Every Moment
hospice
New Zealand

Hospice New Zealand
Standards for palliative care

Quality review programme and guide 2012

Foreword

> **"You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die."**
>
> **– Dame Cicely Saunders**

As the founder of the modern hospice movement, Dame Cicely's words perfectly describe the importance of quality care at the end of life.

The Hospice NZ Standards for Palliative Care have been developed to ensure consistency in the quality of service delivered regardless of locality. The Standards have been developed through collaboration with hospice members, other palliative care providers, audit experts based here in New Zealand and our colleagues at Palliative Care Australia.

Hospice NZ has been responsible for the management of this project, and a governance group has overseen the strategic direction of the project and a working group has supported the content development. The end result is a set of practical and appropriate national standards for the New Zealand healthcare context.

The long term vision for the Standards is that any healthcare provider caring for people with a palliative need can embrace the national standards as a self monitoring performance tool. We see the Standards as being applicable in all settings where a team of people has the desire to evaluate and identify quality improvement areas. Quality improvement practices are an opportunity to reflect on what we do well, validating the care we provide, do more of what works well for people and refine what is not working so well.

The national standards acknowledge that a team of people is required to provide quality care; when we work together we are able to meet the needs of the individual and their family and whānau that are being cared for.

Representing hospices throughout New Zealand, Hospice NZ's vision is that all people in New Zealand have equitable access to the best possible care as they approach the end of their life and die. The Standards build toward that vision and we are committed to their ongoing development and implementation to ensure that the needs of people who are dying are met to a high standard regardless of where they live.

Mary Schumacher
CEO

Wilf Marley
President

Acknowledgements

Hospice New Zealand thanks the organisations and individuals who contributed to the governance and working groups, guiding and shaping the national standards and quality review programme.

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Members roles were at the time of participating in the governance and working groups.

Hospice New Zealand
Standards for palliative care

The quality review programme

The quality review programme guide

Introduction

The development of the national standards and review programme was primarily funded by the Ministry of Health with the aim of supporting quality palliative care in New Zealand. The Hospice New Zealand (HNZ) Standards for providing quality palliative care (the national standards/the Standards), and the HNZ quality palliative care review programme (QRP/the quality review programme) will enable services to undertake a self assessment using standardised tools and processes to determine opportunities for improvement in their performance (the self review) in relation to the fourteen national standards. Peer mentors will then support services with their continuous improvement and assist services to ensure they have carried out a robust self assessment (the peer review).

Hospice New Zealand would like to acknowledge Palliative Care Australia (PCA) for allowing us to use both the PCA Standards and the National Standards Assessment Program (NSAP) as the founding documents and processes for our New Zealand framework. This support enabled us to develop the new edition of the national standards as well as the review programme, for the benefit of all providers of palliative care.

We would like to thank the members of the Standards Governance Group and the Standards Working Group and individuals throughout the palliative care and accreditation sector who have given their time and expertise to this project.

Many individuals and organisations have contributed to the revision of the national standards, including most District Health Boards' (cancer network, district nursing, gerontology, palliative care, and planning and funding teams), general practices and aged residential care facilities. Hospice New Zealand is particularly appreciative of the input from Māori health advisors and Māori palliative care providers on the governance and working groups.

Hospice New Zealand would like to thank the staff of the hospices who participated in the pilot process:

Hospice Marlborough
Hospice Southland
Hospice West Auckland
Hospice Waikato
Lake Taupo Hospice
Mercy Hospice Auckland
North Haven Hospice
Te Omanga Hospice

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Further information relating to the national standards is available on our website:
www.hospice.org.nz

"Mā te wā - everything in its own time"

Introducing Hospice New Zealand

Hospice New Zealand exists to support member hospices in their work caring for people who are dying. We are the national organisation whose primary goal is to give voice to the interests, view and concerns of our member hospices. All hospice services throughout the country are members of Hospice New Zealand – 29 full members and 6 associate members. The Hospice New Zealand purpose, mission, vision values were agreed in consultation with hospice members (2008) and are a reflection of our organisation as a whole.

Our purpose is to ensure all New Zealanders have access to the best possible hospice care at the end of their lives.

Our mission is to be recognised leaders of the hospice movement and support our members:

1. To enhance quality and consistency in the delivery of hospice care
2. To support a high performing hospice/palliative care workforce
3. By advocating for the provision of hospice/palliative care for all New Zealanders and providing central leadership and direction
4. By increasing awareness of hospice in New Zealand
5. By being a highly effective well resourced and well managed national organisation.

All hospices throughout the country share the same vision that anyone who is dying has the opportunity to celebrate their life with the help of hospice.

Our organisational values are a cornerstone to our work:

Patients always come first – every decision we make is based on this belief

Caring – we genuinely care about our people, patients and their families needs

Respect – we demonstrate respect in all our dealings with patients and their families needs, recognising diversity

Professionalism – in all instances we will act professionally and with compassion

Determined – we are driven to work in partnership with our communities

For more information please visit our website **www.hospice.org.nz**

Purpose of the Standards

Hospice New Zealand's vision for the Standards is that all people in New Zealand have equitable access to the best possible care as they approach the end of their life and die.

Quality improvement practices are an opportunity to reflect on what we do well, validating the care we provide, do more of what works well for people and refine what is not working so well. The self assessment framework will be a flexible and enabling process, with many ways to demonstrate or evidence achievement of the Standards.

The first edition of the Standards was released in 1987. The second edition of the Standards was realised in 2001. This third edition of the HNZ Standards has been developed to further support and enhance quality of care for patients with a life limiting condition. Hospices will apply the Standards, and accreditation and audit agencies will be asked to use these Standards as part of their assessment of hospice services.

If we are to make a difference to the quality of palliative care people receive all the time, then the national standards need to be applicable to all settings. Hospice New Zealand has a mandate to produce these national standards for our members and we would welcome and support other providers of palliative care to work towards achieving these also.

The Standards set out the reasonable expectation of quality care for people approaching the end of life, their carer/s, families and whānau. They can be applied to all services caring for people during this time with the exception of children's palliative care services. A process for specialist paediatric palliative care is already in place, this being aligned to the Palliative Care Australia National Standards Assessment Program – Paediatric version, which is available to specialist paediatric palliative care services in Australia and New Zealand. The Paediatric Society of New Zealand through the Palliative Care Special Interest Group supports this involvement with Palliative Care Australia that includes the use of both their paediatric palliative care standards and the associated National Self Assessment Program.

Specialist paediatric palliative care services are encouraged to adopt the paediatric version of the Palliative Care Australia Standards and in using this quality programme will be supported to achieve quality paediatric palliative care.

The Standards, for adult populations, can be used to support quality management, improvement activities and benchmarking at a local, regional or national level.

All hospices throughout New Zealand, as members of Hospice New Zealand are committed to meeting these Standards and will use the quality review programme that sits alongside the Standards.

Ko te puawaitanga o te whakaaro a
tona ua ka huri hei hua

the blossoming of an idea will in time
become the fruits of an endeavour

Overview of the Hospice New Zealand Standards

Standard 1 – Values based care

A competent and compassionate palliative care service provider reflects the philosophy, values, organisational culture, structure and environment in keeping with the core values of quality palliative care.

Standard 2 – Ensuring equitable access

Access to palliative care is available for all people based on need and is independent of current health status, diagnosis, age, cultural background or geography.

Standard 3 – Coordinating care

Care is coordinated to minimise the burden on the patient, their carer/s, family and whānau.

Standard 4 – Providing whole person assessment

All needs of the patient and their family and whānau are acknowledged in the assessment and care planning processes.

Standard 5 – Meeting the cultural needs of diverse family and whānau

The unique cultural needs of the patient and their family and whānau are acknowledged and respected in the assessment and care planning processes.

Standard 6 – Providing person centred care planning

Decision making and care planning is based on a respect for the uniqueness of the patient and their family and whānau.

Standard 7 – Ensuring ongoing assessment and planning

Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient and their family and whānau.

Standard 8 – Caring for patients who are dying

The unique needs of patients in the last days of life, and the family and whānau, are considered, their comfort maximised and their dignity preserved.

Standard 9 – Caring for the carer/s

The carer/s is/are provided with information, support and guidance about their role according to their needs and wishes.

Standard 10 – Providing bereavement care

Formal mechanisms are in place to ensure that the patient and their family and whānau have access to bereavement care, information and support services.

Standard 11 – Building community capacity

Community capacity to respond to the needs of people who have a life limiting condition, and their family and whānau is built through effective collaboration and partnerships.

Standard 12 – Quality and research

The service is committed to quality improvement and research in clinical and management practices.

Standard 13 – Professional development

Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Standard 14 – Reflective practice and self care

Staff and volunteers reflect on their practice and maintain effective self care strategies.

Tēnei te waa - Now is the time

Working with Māori to develop quality palliative care services

These standards align with the principles of the Treaty of Waitangi, and invite hospices to engage with Māori to work collaboratively, in partnership and provide best care and outcomes for the patient/tāoro and family and whānau. Hospice New Zealand acknowledges the unique partnership with Māori. This partnership acknowledges Māori as tangata whenua of Aotearoa/New Zealand and as a self determining people when it comes to caring for their whānau.

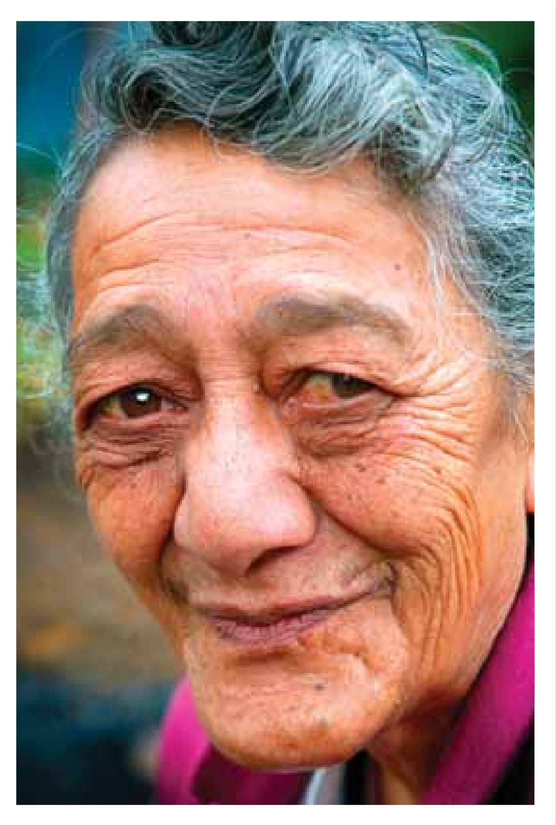
Hospice New Zealand has incorporated advice from our Māori reference group and understands that engagement with Māori is influenced by how we engage, where we engage, when and with whom. These same elements will become the indicators of successful collaboration and partnership. Engagement at a national and local level with respected representatives of Māori will result in a partnered process and ultimately better care. Through partnership we will improve access to services for Māori, expanding peoples' beliefs of what quality palliative care means. Through two way mentoring and education a bicultural partnership will improve outcomes for both parties.

Palliative care services recognise that people are much more than their physical bodies. Our minds, our spirits, our emotions are part of who we are, as are the families and the communities to which we belong. So the problems facing a person with a life limiting condition and their family are not just physical; they may be psychological, social and spiritual issues which are just as important as the condition itself; sometimes problems in one area may worsen others. It is only when we address all these areas that we are helping the whole person. Care for people approaching the end of life is patient centred rather than disease centred and the unit of care is the patient and his/her whānau.

This holistic approach to care has an affinity with the Māori Health Model, Te Whare Tapa Whā (a four sided house). Te Whare Tapa Whā explains an indigenous model of health promotion, comparing good health to the four sides of a house – all four being necessary to ensure strength and symmetry, though each representing a different dimension. It prescribes a balance between taha wairua (spiritual wellbeing), taha hinengaro (intellectual and emotional wellbeing), taha tinana (physical wellbeing) and taha whānau (family/human relationships).

Quality palliative care for Māori is best supported by Tikanga guidelines of care and recommended ways to honour Māori values and beliefs into frontline service delivery. The aim is to ensure the spiritual (wairua), psychological (hinengaro) and physical (tinana) wellbeing of Māori patients (tāroro) and their family (whānau) is upheld. It is acknowledged that some iwi will have differing protocols and customs and therefore services will develop their own guidelines in partnership with local iwi.

The Standards will guide services to continue to develop models of care that begin to address the pathways for action as set out in He Korowai Oranga: Māori Health Strategy (2002). The national standards reinforce this strategy by encouraging increased Māori participation in decision making, planning and delivery of health services; thereby improving access and supporting whānau ora (Māori health and wellbeing).



Taha wairua – Spiritual wellbeing is the capacity for faith and wider communication. 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 wellbeing 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 and soul.

Taha tinana – Physical wellbeing has the capacity for physical growth and wellbeing. Our physical being supports our essence and shelters us from the external environment. For Māori the physical dimension is just one aspect of health and wellbeing and cannot be separated from the aspect of mind, spirit and family.

Taha whānau – Family/human relationships provide a capacity to belong, to care and to share where individuals are part of wider social systems. Whānau provide us with strength to be who we are. This is the link with our ancestors our ties with the past, the present and the future.

For many Māori, modern health services lack recognition of taha wairua (the spiritual dimension). In a traditional Māori approach, the inclusion of the wairua, the role of the whānau and the balance of the hinengaro (mind) are as important as the physical manifestations of illness. Durie, Mason, The Whare Tapa Whā, Tirohanga Māori, Māori Health perspectives, Extracts from Chapter 5 of ‘Whaiora’

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

Other definitions of palliative care

New Zealand has the advantage of exposure to the holistic Māori philosophy/model, Te Whare Tapa Wha and many services have incorporated these health and wellbeing concepts into their own frameworks of care. Also guiding these frameworks are both local and international definitions of care.

New Zealand Palliative Care: a working definition (2007)

This definition remains relevant. Care for people of all ages with a life limiting condition which aims to:

1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs
2. Support the individual's family, whānau, and other carers 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 may be.

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. These include Māori, children and young people, immigrants, refugees, and those in isolated communities.
(Palliative Care Subcommittee, 2007)

World Health Organisation (2002)

This definition recognises that the provision of palliative care is applicable at any stage after diagnosis of a life limiting condition:

"Palliative care is an approach that improves the quality of life of patients and their families facing a life threatening condition, 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."
(WHO, 2002) see glossary for a full definition

Tuku whaka oki oki

Palliative care - to give comfort

Applying the Standards to all populations

Special consideration needs to be given to particular groups in our community when applying the Standards. The total New Zealand population referred to is 4,184,590 (Census 2006). In 2006 the estimated percentage of people aged 65 and over in New Zealand was 12.2%, and 1.4% were over 85. This is projected to increase to 18.9% and 2.3% respectively by 2026 with a corresponding reduction in the proportion of the younger age groups. The changing age demographic of the New Zealand population is of significant concern to health services. As more people live longer there is likely to be a rise in chronic conditions – such as heart conditions, cerebrovascular conditions, respiratory conditions and cancer, all leading to an increased need for health care and a corresponding increase in need for palliative and end of life care. New Zealand has a very diverse ethnic makeup. The majority of people identify as New Zealander, NZ European or European (67%), followed by Māori (14%) and Pacific (5.6%). The other major ethnic groups include Chinese (3.4%), Indian (2.5%) and Other Asian (2.6%).

All people have cultural needs

Palliative care services are encouraged to provide care free of assumptions based on ethnicity or culture, instead exploring and discussing the individual needs of those in the service. Each and every person receiving services from a palliative care team has the right to be treated as an individual, with recognition of needs and wishes not only unique to their culture but unique to the individual. Much work has been done in identifying frameworks that are useful in providing care to people of different ethnicities. These tools assist services in delivering quality care, not limiting choices, but providing a starting point for further exploring the personal preferences of an individual.

Tangata whenua – whānau who identify as Māori

All models of indigenous care, at their core, will contain the interrelated dimensions of the physical, spiritual, familial and environmental realms. These principles are evidenced in the Te Whare Tapa Whā model of health care for Māori, however, local iwi/hapū/whānau may have variations of health care models which they practise. Each hospice has the responsibility to develop partnerships with local iwi/hapū service providers. It is important to recognise the diversity of backgrounds and experiences of Māori people in New Zealand; there is also a wide range of interpretations of these experiences in determining what being Māori means to the individual. Avoiding cultural assumptions is necessary to achieve the best possible outcomes for the individual/s, whānau and communities. At all times the whānau will determine their cultural identity and needs. It is up to hospices to meet the diverse cultural needs of all whānau.

People from Pacific Island nations

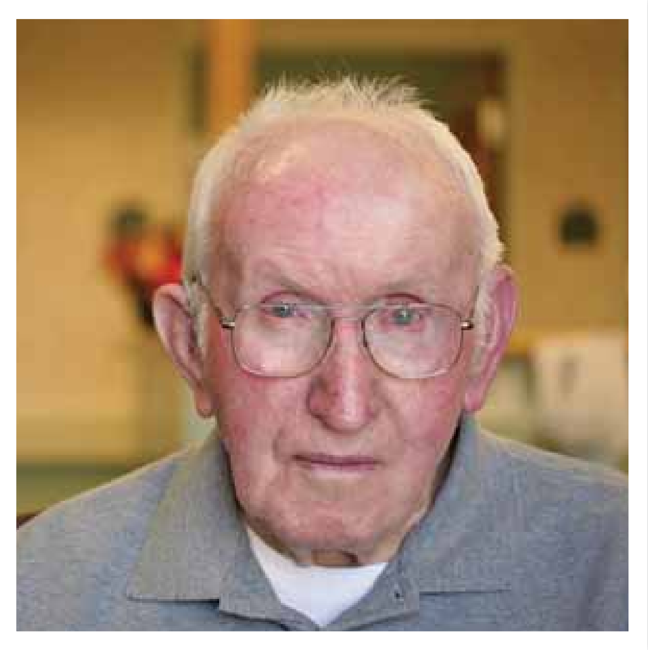
Pacific peoples in New Zealand are immensely diverse – culturally and socially. Understanding Pacific people's personal perceptions and cultural beliefs about their health is crucial to understanding individuals', families' and communities' use of health services and expectations of quality care. Pacific models of health care have been developed which recognise Pacific world views and beliefs about health. The 'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2010-2014 outlines principles of respecting pacific culture, valuing family, quality health care, and working together. Palliative care services need to ensure they consult and collaborate with Pacific peoples to ensure access to appropriate cultural support and advocacy.

People from culturally and linguistically diverse (CALD) backgrounds

With the growing Asian, migrant and refugee population across New Zealand, health practitioners are having more and more cross-cultural interactions with migrant and refugee health clients from different culture and language backgrounds. Cultural knowledge and awareness is essential when working with CALD people to improve the interactions and relationships when negotiating and agreeing care. Palliative care services need to collaborate with ethnic groups in the region to determine service delivery and to reduce barriers to access.

Non-malignant conditions

People with age related functional changes or with chronic conditions such as diabetes, heart, respiratory and neurological conditions will all benefit from quality palliative care services, provided according to the individual's specific needs. It is important that this group of people are offered a palliative approach to care, with referral to specialist palliative care services as required. A palliative approach can be used alongside active ongoing care.



People who live in aged residential care facilities

For some people a residential aged care facility will be their home, with some admitted for palliative and end of life care and others who are residents for many years before needing a palliative approach. It is important that residents of residential aged care facilities have access to appropriate and adequate levels of support from primary care services, general practitioners and residential aged care staff, and access to consultative support or direct care from specialist palliative care teams, depending upon their level of need.

Adults who live with disability

One in five New Zealanders has a long term impairment. They may be physical, sensory, neurological, psychiatric, intellectual or other impairments. All New Zealanders need to consider issues for disabled people and their aspirations as individuals. We must also consider the families and whānau of disabled people, and others who support them. Palliative care services need to ensure they consider disabled people before making decisions about care delivery frameworks, and when negotiating and agreeing care with patients and family/whānau with disability needs.

Adults who have limited or no capacity to make informed choices

In order for a patient to be autonomous or to make competent decisions in their own interest, they must be fully informed of the facts and probabilities, able to understand, able to make a voluntary and reasoned choice and be able to communicate that choice. Managing the needs of patients with a life limiting condition who are not able to make informed decisions on their own behalf – for example patients with dementia or intellectual disability, requires careful attention to the decision making and care delivery process. Patients should be afforded every possible opportunity to contribute as far as they are able, to care planning and decision making.

People with mental health needs

Providing services to people with a mental health condition can create access and management challenges for palliative care services and patients. It is known that many people with mental health needs have difficulty gaining appropriate identification, assessment and care of their physical needs and may not receive diagnosis until late in an illness trajectory. Furthermore, people with mental health needs may have poorly met social, housing, income and support needs. Partnerships between mental health, the social service sector and palliative care services are necessary in most cases, to achieve optimal patient outcomes.

People who live in other institutions or who are homeless

Some people die in institutions such as prisons, shared or group homes or hostels or are homeless. It is important that services be flexible enough to meet the needs of these potentially highly vulnerable people. Partnerships between health and community services should be in place to ensure that the needs of these people can be met.

Excluded from these Standards

Children with a life limiting condition

The Association for Children's Palliative Care (ACT) and the Royal College of Paediatrics and Child Health define palliative care for children and young people with life limiting conditions as an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the child and support for the whole family and includes the management of distressing symptoms, provision of respite and care from diagnosis through death and bereavement.

Life limiting conditions are those for which there is no reasonable hope of cure and from which children will die. Many of these conditions cause progressive deterioration, rendering the child increasingly dependent on parents and caregivers.

Children’s disease trajectories are often long in their course and uncertain in their prognosis. Children who might once have died in childhood now live for very long periods, with implications for families, caregivers and services. Childhood influences the experience of disease. The developmental level of the child affects the way illness and death are discussed, how the information is provided and received, the level to which a child can participate in decision making and how pain and other symptoms are assessed and managed. Specific problems for children/young people include pain perception and memory, nutrition, nausea and vomiting and neurological problems such as seizures. Death of a child/young person is devastating for families/whānau, and bereavement care is an essential component of paediatric palliative care.

Paediatric palliative care requires integrated, flexible services that are able to respond to changing needs of children/young people and their families/whānau. Good services link with primary providers and appropriately engage across the disease trajectory, whether the end point is death or recovery.

New Zealand services providing paediatric palliative care are encouraged to find out more about the PCA NSAP – paediatric version.

Mōku anō ēnei rā, mo te rā
ka hekeheke; he rākau ka
hinga ki te mano wai!

Let these few days be for
me, for the declining sun;
a tree falling through
many floods of waters

Hospice New Zealand Quality Review Programme

The HNZ quality review programme (QRP/the standards review programme) will enable services to undertake a self review using standardised tools and processes to determine opportunities for improvement in their performance (the self review) in relation to the fourteen national standards. Peer mentors will then support services with their continuous improvement and assist services to ensure they have carried out a robust self assessment (the peer review).

Therefore the quality review programme has two components: the self review; and the peer review. The following is the description of the Standards and the tool for review actitivities.

Understanding and navigating the Standards

The components of the Standards and the purpose of each of the components are described in the table below:

Standard	Contains the specific Standard.
Intent	A series of statements that provide further details as to the intent of the Standard to assist with interpretation.
Quality elements	The elements of the Standard that will be assessed and evidenced.

Capabilities of services

Access to quality care for people approaching the end of their life, their carer/s, family and whānau is a right of all people who live in New Zealand. The level and complexity of the needs of the patient and family and whānau will determine the appropriate level of service response. The following articulates and describes the unique and interwoven roles of primary care services and specialist palliative care services in collaborative efforts to provide high quality palliative care and end of life care to all people of New Zealand. The table below describes the roles and responsibilities of these services:

All palliative care capability

- Provides clinical management and care coordination including assessment and care provision for patients with needs associated with palliative and end of life care.
- Care might include referral to other services, including hospice.

Specialist care capability

- Provides comprehensive care for patients, carer/s, families and whānau whose complex needs exceed the capability of primary care services.
- Has links to primary care services and other specialist care services for consultative support and advice to meet the needs of patients, families and whānau.
- Supports the provision of quality care by participating in the delivery of education for other palliative care services.
- Has links with other hospices and specialist care services in the region, primary care services and other specialties.

Discretionary capability

- Supports the delivery of education programmes to all providers of palliative care and the community across a network or region.
- Supports and leads the achievement of standards and development in palliative care across a network or region.
- Has formal links with relevant academic units and has a research role.

Understanding and navigating the review tool

The additional components that relate to the self review tool are described in the table below:

Evidence sources	Data and information that should be accessed and used as part of the assessment of this standard: • Primary evidence – clinical audit and statistical data (for example, administrative data collections, patient and family survey results) • Secondary evidence – for example policies and procedures, mission statements • Accreditation evidence – evidence that has been compiled for the purposes of accreditation can also be used to assess the standard
Results table	A table to document assessment results and to record the key points supporting ratings
Priority rating	A rating that indicates the assessed priority for improvement actions within the service for each national standard

Using the rating scale

For each quality element, the review team are asked to rate the services performance. The following descriptions of each rating will be used when determining the appropriate rating for each quality element.

Never – means that this does not occur
Rarely – means that this occurs less than 25% of the time
Sometimes – means that this occurs between 25-75% of the time
Often – means that this occurs over 75% of the time
Always – means that this occurs all the time

Some of the quality elements contain multiple aspects, and the rating allocated by the team should consider the services performance against all aspects of the element. Ratings of ‘always’ should only be applied when all aspects of the element are achieved. Where aspects are assessed differently the overall rating for the element should reflect the lowest rated aspect.

He toka tū moana, arā he toa rongonui

Your strength is like a rock that stands in raging waters

Using the priority rating

For each standard, the team are asked to assign a rating that indicates the assessed priority for improvement actions within the service for each national standard. Many local factors will influence how an identified opportunity for improvement is prioritised within an organisation. Some elements may not be able to be addressed by local initiatives. The allocation of a priority would include an assessment of the impact on patient and family and whānau experience, organisational strategic and operational plans and the availability of resources. Within each review cycle many opportunities for improvement will be identified but not all of these would be able to be actioned within the improvement cycle. The priority rating assists the service to develop an actionable quality improvement plan at the end of the assessment process that will produce achievable improvement in the quality of care being provided.

The following description of each priority rating will be used when determining the appropriate rating for each standard:

Rating	Meaning	When would this rating be most appropriate?
High	This is a high priority area for quality improvement initiatives. The self review has found that there is good scope for local initiatives which will improve outcomes for patients.	A high priority rating would be appropriate when there is evidence of a locally actionable improvement opportunity that is consistent with the organisations strategic and operational plans. Assessment of opportunities for improvement that have a direct impact on patient experience should attract a high priority rating (for example improving information resources for families).
Medium	This is medium priority area for quality improvement. Quality improvement initiatives will be implemented after high priority areas have been addressed.	A medium priority rating would be appropriate when there is evidence of a locally actionable improvement opportunity that may not be assessed as having a direct impact on patient and family experience (for example development of policies).
Low	This is low priority for quality improvement initiatives. The self review has found that in general the current procedures and practices deliver high quality services to patients for this standard.	A low priority rating would be appropriate when the evidence identifies opportunities for improvement that do not directly affect patient and family experience and are of lesser importance to the overall organisation strategic or operational goals. A low priority rating may be applied where it is assessed that there is no opportunity for local improvement actions.

Standard 1:
Values based care

Standard	A competent and compassionate service provider reflects the philosophy, organisational culture, structure and environment in keeping with the core values of quality palliative care.
Intent	“Palliative care begins from the understanding that every person has his or her own story, relationships and culture, and is worthy of respect as a unique individual.” [1] The core values of the service embrace that every decision is based on the belief that patients come first, we genuinely care about people, patients and their families’ and whānau needs, we demonstrate respect in all our dealings with patients, families and whānau , in all instances we will act professionally and with compassion, and we work in partnership with our communities. Care at the end of life aims to relieve suffering and improve the quality of living and dying. Palliative care strives to help patients and their family/whānau to address physical, psychological, cultural, social, spiritual and practical issues, and their associated expectations, needs, hopes, and fears. The palliative care service will provide support to the patient, family and whānau to prepare for and manage end of life and the dying process and with loss and grief during the illness and bereavement. Palliative care may complement and enhance disease-modifying therapy or it may be the total focus of care. Specialist care is most effectively delivered by an interdisciplinary team of health care providers who are both knowledgeable and skilled in all aspects of their discipline of practice as it relates to end of life care. Effective communication, group function and the ability to promote and manage change are important elements in interdisciplinary teamwork. When patients do not require specialist palliative care a palliative approach should be adopted by primary care providers and other specialists.

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[1] WHO (2004). The Solid Facts: Palliative Care. Accessible on the internet www.euro.who.int Randall, F. Downie, R.S. (2006). The philosophy of palliative care. Oxford.

Possible sources of evidence for Standard 1

Evidence source	Quality Element					
Audit/statistical data	**1.1**	**1.2**	**1.3**	**1.4**	**1.5**	**1.6**
Community population demographics						
Patient and family survey	✘	✘	✘	✘		
Staff and volunteer survey	✘					
Environmental survey	✘	✘	✘	✘		✘
Benchmarking data	✘					
Clinical indicators						
Clinical audit	✘		✘	✘		
Quality improvement project outcomes						
Other sources						
Patient records/assessments	**1.1**	**1.2**	**1.3**	**1.4**	**1.5**	**1.6**
Clinical records review						
Assessment and care planning procedures		✘		✘		
Documentation procedures						
Validated tools used						
Other sources						
Business records	**1.1**	**1.2**	**1.3**	**1.4**	**1.5**	**1.6**
Organisation statements (vision, mission, business plan etc)	✘	✘				✘
Organisation policies and procedures	✘	✘	✘	✘		
Review and analysis of clinical incidents			✘	✘		
Review and analysis of complaints			✘			
Review of out of hours contact records				✘		
Access arrangements to community and support services		✘				
Minutes of interdisciplinary meetings		✘	✘			
Agreements with external service providers	✘					
Agreements with primary health care providers						
Agreements with cultural resource providers						
Induction and other training packages for staff and volunteers					✘	
Training packages for primary caregivers					✘	
Training packages for external health care service providers					✘	
Professional development programmes					✘	
Personnel records						
Records of staff meetings						
Attendance at staff and volunteer education events						
Minutes of committee meetings						✘
Evidence of formal accreditation						
Formal arrangements with education institutions						
Records of educational events					✘	✘
Use of standardised national education resources					✘	
Information and resource materials for patients and families	✘		✘			
Other sources						

Recording the results of the assessment of Standard 1

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
1.1	**All palliative care and specialist care service elements** The service has a written vision, mission and objectives which are incorporated across the organisation.						
1.2	When possible the care is provided in the setting preferred by the patient and their family and whānau .						
1.3	The care setting provides an appropriate environment to support patient and family interaction and comfort.						
1.4	The care setting provides a safe environment for patients, families and staff.						
1.5	**Specialist care service elements** The national standards form part of the service's philosophy and training programme for staff.						
1.6	**Discretionary elements** The service leads the development of networks at regional, and participates at national and international levels to improve the future quality of palliative care delivery.						

Overall priority rating for standard (circle): High Medium Low

Standard 2:
Ensuring equitable access

Standard	Access to palliative care is available for all people based on need and is independent of current health status, diagnosis, age, income, cultural background or geography.
Intent	Palliative care services are actively involved in the development of policies and structures that increase equity of access to services based on level of need. Palliative care services at all levels have formal links that facilitate patient and family access to more or less complex care based on level of need. Direct care from a specialist palliative care service may be episodic rather than ongoing, and based on specific complex needs. Specialist palliative care services support the work of primary care services through the availability of direct consultation and training. Specialist palliative care services acknowledge the demographic needs within their own regions through flexible services to promote access for a range of ethnic groups.

Ministry of Health, (2001). *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
Palliative Care Council of New Zealand, (2011). *National health needs assessment for palliative care*. Wellington: Palliative Care Council of New Zealand.

Possible sources of evidence for Standard 2

Evidence source	Quality Element										
Audit/statistical data	2.1	2.2	2.3	2.4	2.5	2.6	2.7	2.8	2.9	2.10	2.11
Community population demographics											✘
Patient and family survey	✘	✘	✘		✘	✘		✘	✘	✘	
Staff and volunteer survey		✘			✘	✘		✘			✘
Environmental survey	✘		✘	✘							✘
Benchmarking data					✘				✘		
Clinical indicators											
Clinical audit					✘		✘				
Quality improvement project outcomes											
Other sources											
Patient records/assessments	2.1	2.2	2.3	2.4	2.5	2.6	2.7	2.8	2.9	2.10	2.11
Clinical records review					✘						
Assessment and care planning procedures					✘						
Documentation procedures					✘						
Validated tools used					✘						
Other sources											
Business records	2.1	2.2	2.3	2.4	2.5	2.6	2.7	2.8	2.9	2.10	2.11
Organisation statements (vision, mission, business plan etc)		✘			✘			✘		✘	✘
Organisation policies and procedures	✘	✘	✘		✘	✘	✘			✘	
Review and analysis of clinical incidents											
Review and analysis of complaints	✘	✘	✘			✘					✘
Review of out of hours contact records		✘				✘				✘	✘
Access arrangements to community and support services											
Minutes of interdisciplinary meetings		✘									
Agreements with external service providers		✘				✘			✘	✘	✘
Agreements with primary health care providers		✘				✘			✘	✘	✘
Agreements with cultural resource providers	✘		✘	✘		✘					✘
Induction and other training packages for staff and volunteers	✘		✘								
Training packages for primary caregivers	✘		✘								
Training packages for external health care service providers											
Professional development programmes											
Personnel records	✘		✘								
Records of staff meetings											
Attendance at staff and volunteer education events											
Minutes of committee meetings											
Evidence of formal accreditation											
Formal arrangements with education institutions											
Records of educational events											
Use of standardised national education resources											
Information and resource materials for patients and families											
Other sources											

Recording the results of the assessment of Standard 2

	Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*	**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
2.1	**All palliative care and specialist care service elements** Policies and procedures are in place to ensure services are available and easily accessible to all people.						
2.2	Respite care services (primary and specialist) are available for the family/whānau and carers.						
2.3	The service can accommodate the language, dietary and ritual practices of patients and their familes and whānau .						
2.4	The team has access to interpreter services.						
2.5	**Specialist care service elements** The service supports and promotes continuity of care across settings and throughout the course of the patient's life limiting condition.						
2.6	The service leads the development of networks at regional, and participates at national and international levels to improve the future quality of palliative care delivery.						
2.7	Policies for prioritising and responding to referrals in a timely manner are documented.						
2.8	The profile of population accessing the service is compared with those in the community and inequities of access addressed.						
2.9	Where demand for palliative care services exceeds capacity, there are strategies in place with other organisations to meet needs.						
2.10	Patients and families have access to palliative care expertise and staff 24 hours per day, seven days per week.						
2.11	**Discretionary elements** The service develops mechanisms to regularly assess unmet need in the local and regional area and provide estimates of future need.						

Overall priority rating for standard (circle): High Medium Low

Standard 3:
Coordinating care

Standard	Care is coordinated to minimise the burden on the patient, their carer/s, family and whānau
Intent	Feedback indicates that lack of coordinated care and services increases the stress experienced by the patient, their carer/s, family and whānau and that alleviation of this would add significantly to their quality of life. Scheduling of care, interventions and/or visits provides opportunities for rest and privacy according to the wishes of the patients and their familes and whānau. Communication between service providers facilitates the smooth and timely delivery of services. The patient and their family and whānau provide informed consent to communication and sharing of information between service providers.

Ministry of Health, (2001). *The New Zealand Palliative Care Strategy*. Wellington: Ministry of Health.
Palliative Care Council of New Zealand, (2011). *National health needs assessment for palliative care*. Wellington: Palliative Care Council of New Zealand.

Possible sources of evidence for Standard 3

Evidence source	Quality Element						
Audit/statistical data	**3.1**	**3.2**	**3.3**	**3.4**	**3.5**	**3.6**	**3.7**
Community population demographics							
Patient and family survey	✘		✘	✘	✘		
Staff and volunteer survey	✘		✘		✘		✘
Environmental survey							
Benchmarking data	✘						
Clinical indicators							
Clinical audit						✘	
Quality improvement project outcomes							
Other sources							
Patient records/assessments	**3.1**	**3.2**	**3.3**	**3.4**	**3.5**	**3.6**	**3.7**
Clinical records review							
Assessment and care planning procedures	✘						
Documentation procedures	✘						
Validated tools used	✘						
Other sources							
Business records	**3.1**	**3.2**	**3.3**	**3.4**	**3.5**	**3.6**	**3.7**
Organisation statements (vision, mission, business plan etc)							
Organisation policies and procedures	✘		✘	✘	✘		
Review and analysis of clinical incidents							
Review and analysis of complaints							
Review of out of hours contact records	✘						
Access arrangements to community and support services			✘				
Minutes of interdisciplinary meetings	✘				✘		✘
Agreements with external service providers	✘	✘			✘		✘
Agreements with primary health care providers	✘	✘					✘
Agreements with cultural resource providers	✘	✘					✘
Induction and other training packages for staff and volunteers							
Training packages for primary caregivers							
Training packages for external health care service providers							
Professional development programmes							
Personnel records	✘						
Records of staff meetings	✘						
Attendance at staff and volunteer education events							
Minutes of committee meetings							
Evidence of formal accreditation							
Formal arrangements with education institutions							
Records of educational events							
Use of standardised national education resources							
Information and resource materials for patients and families							
Other sources							

Recording the results of the assessment of Standard 3

	Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*	**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
3.1	**All palliative care and specialist care service elements** The assessment process and care plan reflect a coordinated approach to care delivery that will ensure continuity of care across all required care settings.						
3.2	There are agreements in place with other service providers that clearly set out protocols and procedures outlining roles and responsibilities that will support quality care.						
3.3	Referrals are made to appropriate services to meet the identified social needs of the patient and their family and whānau .						
3.4	Discharge plans and/or plans for referral to another service are discussed with the patient and family to ensure they accommodate their needs and wishes.						
3.5	**Specialist care service elements** There is an identified care coordinator (e.g. lead agency or clinician) who takes responsibility for the overall plan of care.						
3.6	Ongoing service review is undertaken to improve efficiency in delivery of services.						
3.7	**Discretionary elements** The service will undertake initiatives that improve understanding of local and regional needs to improve outcomes for palliative care patients and their familes and whānau .						

Overall priority rating for standard (circle): High Medium Low

Standard 4: Providing whole person assessment

Standard	All needs of the patient and their family and whānau are acknowledged in the assessment and care planning processes.
Intent	Health care providers use sensitive communication skills and allow sufficient time to enable patients to express all their needs and/or offer referral to appropriate support and/or counselling services.[2] Health care providers make available information resources and other options so that the patient and their family and whānau can make informed choices. It is recognised that the patient and their family and whānau also have strengths and expertise in managing their own care. Members of the interdisciplinary team offer a diverse range of skills in the provision of emotional, social, psychological, cultural, religious and spiritual support, and it is recognised that all team members play a vital role.

Ministry of Health (2003). *The Cancer Control Strategy*. Wellington: Ministry of Health.

[2] Saunders C. (1993). Foreword to *Oxford Textbook of Palliative Medicine*, 1st edn, ed, Doyle, D.Hanks, G. MacDonald, N. Oxford: Oxford University Press.

Egan, R., MacLeod, R., Jaye, C., McGee, R., Baxter, J., & Herbison, P. (2011). What is spirituality? Evidence from a New Zealand hospice study. [doi: 10.1080/13576275.2011.613267]. *Mortality*, 16(4), 307-324.

Possible sources of evidence for Standard 4

Evidence source	Quality Element					
Audit/statistical data	**4.1**	**4.2**	**4.3**	**4.4**	**4.5**	**4.6**
Community population demographics						
Patient and family survey		✘	✘			
Staff and volunteer survey						
Environmental survey	✘	✘	✘	✘	✘	
Benchmarking data		✘	✘			
Clinical indicators						
Clinical audit	✘	✘	✘	✘	✘	
Quality improvement project outcomes						
Other sources						
Patient records/assessments	**4.1**	**4.2**	**4.3**	**4.4**	**4.5**	**4.6**
Clinical records review	✘	✘	✘	✘	✘	
Assessment and care planning procedures	✘	✘	✘	✘		
Documentation procedures	✘	✘	✘	✘	✘	
Validated tools used	✘	✘	✘	✘	✘	
Other sources						
Business records	**4.1**	**4.2**	**4.3**	**4.4**	**4.5**	**4.6**
Organisation statements (vision, mission, business plan etc)						
Organisation policies and procedures						
Review and analysis of clinical incidents						
Review and analysis of complaints			✘			
Review of out of hours contact records						
Access arrangements to community and support services						
Minutes of interdisciplinary meetings	✘	✘		✘		
Agreements with external service providers						✘
Agreements with primary health care providers						✘
Agreements with cultural resource providers						
Induction and other training packages for staff and volunteers						✘
Training packages for primary caregivers						✘
Training packages for external health care service providers						
Professional development programmes						
Personnel records						
Records of staff meetings						
Attendance at staff and volunteer education events						
Minutes of committee meetings						
Evidence of formal accreditation						
Formal arrangements with education institutions						
Records of educational events						
Use of standardised national education resources						
Information and resource materials for patients and families						
Other sources						

Recording the results of the assessment of Standard 4

	Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*	**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
4.1	**All palliative care and specialist care service elements** The first assessment is interdisciplinary, coordinated and documented.						
4.2	Treatment and care are individualised with consideration of the patients' needs and preferences (physical, social, cultural, emotional, psychological and spiritual).						
4.3	The assessment of the patient and family expectations includes preferences for the type of support and place of care and these are documented.						
4.4	The patient assessment is reviewed and updated on a regular basis based on patient condition and need.						
4.5	Validated clinical assessment tools are used where they are available (see Hospice NZ website for a list of validated tools).						
4.6	**Specialist care service elements** There are agreements in place to support primary care services to achieve improved outcomes for patients and their familes and whānau.						

Overall priority rating for standard (circle): High Medium Low

Standard 5:
Meeting the cultural needs of diverse family and whānau

Standard	The unique cultural needs of the patient and their family and whānau are acknowledged and respected in the assessment and care planning processes.
Intent	Open and respectful communication with the patient and their family and whānau will have practices that will be beneficial to holistic wellbeing. Services for Māori will be provided in a manner that honours the Treaty of Waitangi based on the principles: participation at all levels; partnership in service delivery; and protection and improvement of Māori wellbeing. The culture and personal meanings disclosed or made evident during interaction with a service provider are integrated into the overall assessment and care planning of the patient and whānau. Cultural competence is the ability of individuals and systems to respond respectfully and effectively to people of all cultures, races, classes and ethnic backgrounds and religions in a manner that recognises, affirms, and values the cultural similarities and differences and their worth.[3] Diversity of family structures and decision making processes across ethnicities and cultures will be incorporated into care planning.

Possible sources of evidence for Standard 5

Evidence source	Quality Element									
Audit/statistical data	**5.1**	**5.2**	**5.3**	**5.4**	**5.5**	**5.6**	**5.7**	**5.8**	**5.9**	**5.10**
Community population demographics		✘	✘							
Patient and family survey	✘	✘	✘							
Staff and volunteer survey					✘					
Environmental survey	✘									
Benchmarking data			✘							
Clinical indicators										
Clinical audit	✘									
Quality improvement project outcomes	✘			✘						
Other sources										
Patient records/assessments	**5.1**	**5.2**	**5.3**	**5.4**	**5.5**	**5.6**	**5.7**	**5.8**	**5.9**	**5.10**
Clinical records review	✘	✘						✘		
Assessment and care planning procedures	✘	✘								
Documentation procedures	✘	✘								
Validated tools used	✘	✘								
Other sources										
Business records	**5.1**	**5.2**	**5.3**	**5.4**	**5.5**	**5.6**	**5.7**	**5.8**	**5.9**	**5.10**
Organisation statements (vision, mission, business plan etc)	✘			✘			✘			
Organisation policies and procedures	✘			✘		✘	✘	✘		
Review and analysis of clinical incidents	✘									
Review and analysis of complaints	✘							✘		
Review of out of hours contact records										
Access arrangements to community and support services	✘		✘	✘			✘			
Minutes of interdisciplinary meetings	✘	✘								
Agreements with external service providers	✘		✘	✘						
Agreements with primary health care providers	✘		✘	✘						
Agreements with cultural resource providers	✘		✘	✘						
Induction and other training packages for staff and volunteers	✘									
Training packages for primary caregivers	✘		✘							
Training packages for external health care service providers	✘			✘						
Professional development programmes	✘									
Personnel records										
Records of staff meetings										
Attendance at staff and volunteer education events										
Minutes of committee meetings			✘							
Evidence of formal accreditation										
Formal arrangements with education institutions										
Records of educational events										
Use of standardised national education resources	✘									
Information and resource materials for patients and families										
Other sources										

Schwass, M. (2005). Last Words: *Approaches to death in New Zealand cultures and faiths*. Bridget Williams Books with the Funeral Directors Association of New Zealand.

Ministry of Health (2002). *He Korowai Oranga:* Māori *Health Strategy*. Wellington: Ministry of Health.

[3] Tse, S., Bhui, K., Thapliyal, A. (2005). *Asian Mental Health Workforce Development Feasibility Project*. Auckland: Health Research Council of New Zealand.

Recording the results of the assessment of Standard 5

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
5.1	**All palliative care and specialist care service elements** Patients and whānau have access to appropriate cultural and ethnic support and advocacy.						
5.2	There is identification and documentation of specific cultural needs.						
5.3	The service collaborates with ethnic groups in the region in determining service delivery and reducing barriers to access.						
5.4	The service enters into partnership with local Māori and through this engagement builds a Māori health plan.						
5.5	Staff and volunteers from all ethnic backgrounds are supported to develop their palliative care skills and knowledge.						
5.6	Staff are offered and encouraged to participate in cultural supervision, where appropriate.						
5.7	**Specialist care service elements** There is a kaumātua at the governance level of the organisation to provide advice.						
5.8	There is a dedicated Māori advisory position or ability to access and consult with Māori.						
5.9	There is a Māori health plan that is developed in partnership with local Māori health providers and whānau and implemented by the service.						
5.10	**Discretionary elements** Research projects assist increased access to palliative care by all cultural and/or ethnic groups.						

Overall priority rating for standard (circle): High Medium Low

Standard 6:
Providing person centred care planning

Standard	Decision making and care planning is based on a respect for the uniqueness of the patient and their family and whānau.
Intent	The uniqueness of each patient and their family and whānau is respected, as is the importance of the community to which they belong. The patient and their family and whānau are considered the unit of care. Therefore the needs of individual members of the unit of care need to be identified and addressed individually and balanced with the service provider's legal and professional responsibilities. Information about the needs of the patient, and their family and whānau is gathered at an appropriate time, recognising the complexity of issues, the readiness of the patient and their family and whānau, and the burden the assessment process itself can place on them. Comprehensive and interdisciplinary care planning is essential for specialist palliative care.

Nay, R et al (2009). *Person Centred Care*. Chapter 7, Older People: Issues and innovations in care. Australia: Elsevier.

Rogers, J., Niven, E. (1996). *Ethics: a guide for New Zealand nurses*. New Zealand: Longman.

Possible sources of evidence for Standard 6

Evidence source	Quality Element						
Audit/statistical data	**6.1**	**6.2**	**6.3**	**6.4**	**6.5**	**6.6**	**6.7**
Community population demographics							
Patient and family survey	✘	✘	✘	✘	✘		
Staff and volunteer survey							
Environmental survey	✘	✘	✘	✘	✘	✘	✘
Benchmarking data							
Clinical indicators							
Clinical audit	✘		✘	✘		✘	
Quality improvement project outcomes							
Other sources							
Patient records/assessments	**6.1**	**6.2**	**6.3**	**6.4**	**6.5**	**6.6**	**6.7**
Clinical records review	✘		✘	✘		✘	
Assessment and care planning procedures	✘		✘		✘		
Documentation procedures	✘		✘		✘		
Validated tools used	✘		✘			✘	
Other sources							
Business records	**6.1**	**6.2**	**6.3**	**6.4**	**6.5**	**6.6**	**6.7**
Organisation statements (vision, mission, business plan etc)							
Organisation policies and procedures							
Review and analysis of clinical incidents							
Review and analysis of complaints			✘		✘		
Review of out of hours contact records							
Access arrangements to community and support services							
Minutes of interdisciplinary meetings		✘	✘			✘	
Agreements with external service providers							
Agreements with primary health care providers							
Agreements with cultural resource providers							
Induction and other training packages for staff and volunteers							
Training packages for primary caregivers							✘
Training packages for external health care service providers							✘
Professional development programmes							✘
Personnel records							
Records of staff meetings							
Attendance at staff and volunteer education events							✘
Minutes of committee meetings							
Evidence of formal accreditation							
Formal arrangements with education institutions							
Records of educational events							✘
Use of standardised national education resources							
Information and resource materials for patients and families							
Other sources							

Recording the results of the assessment of Standard 6

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
6.1	**All palliative care and specialist care service elements** The patient's care plan takes into consideration the patient and family and whānau's description of their experience and needs.						
6.2	The patient (or an appropriate proxy) and family and whānau priorities and plans are discussed and documented.						
6.3	Variation from the documented patient preferences about care is documented and reviewed by the team.						
6.4	The patient with decisional capacity determines the involvement of the family in decision making and communication about the care plan.						
6.5	The patient and their family and whānau are provided with up to date and appropriate information to meet their needs and support their participation in care planning and decision making.						
6.6	The interdisciplinary team communicates the palliative care plan, with patient approval, to all involved health professionals when patients' transfer to different care settings.						
6.7	**Specialist care service elements** Services provide care planning education to other services providing palliative care.						

Overall priority rating for standard (circle): High Medium Low

Standard 7:
Ensuring ongoing assessment and planning

Standard	Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient and their family and whānau.
Intent	The needs, strengths, understandings and expectations of the patient and their family and whānau are documented and reflected upon in the assessment. The patient and their family and whānau are encouraged to express their care needs during the assessment and care planning process. Health care providers performing this function are flexible in timing and methods so that the assessment is as unobtrusive as possible. The ongoing gathering and recording of information is considered to be an integral part of assessment and care planning. Where discharge from the service is anticipated a comprehensive discharge plan is initiated on admission. Discussion and documentation of the patient, and their family and whānau wishes about end of life care is begun if/when appropriate.

Possible sources of evidence for Standard 7

Evidence source	Quality Element			
Audit/statistical data	**7.1**	**7.2**	**7.3**	**7.4**
Community population demographics				
Patient and family survey	✘		✘	✘
Staff and volunteer survey				
Environmental survey	✘		✘	
Benchmarking data				
Clinical indicators				
Clinical audit	✘	✘	✘	✘
Quality improvement project outcomes				
Other sources		✘		✘
Patient records/assessments	**7.1**	**7.2**	**7.3**	**7.4**
Clinical records review	✘	✘	✘	✘
Assessment and care planning procedures	✘	✘	✘	✘
Documentation procedures	✘	✘	✘	✘
Validated tools used	✘	✘	✘	
Other sources				
Business records	**7.1**	**7.2**	**7.3**	**7.4**
Organisation statements (vision, mission, business plan etc)				
Organisation policies and procedures	✘	✘		✘
Review and analysis of clinical incidents				
Review and analysis of complaints		✘	✘	
Review of out of hours contact records		✘		
Access arrangements to community and support services				
Minutes of interdisciplinary meetings		✘	✘	✘
Agreements with external service providers				
Agreements with primary health care providers				
Agreements with cultural resource providers				
Induction and other training packages for staff and volunteers				
Training packages for primary caregivers				
Training packages for external health care service providers				
Professional development programmes				
Personnel records				
Records of staff meetings				
Attendance at staff and volunteer education events				
Minutes of committee meetings				
Evidence of formal accreditation				
Formal arrangements with education institutions				
Records of educational events				
Use of standardised national education resources				
Information and resource materials for patients and families				
Other sources				

Recording the results of the assessment of Standard 7

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
7.1	**All palliative care and specialist care service elements** Regular assessment of pain and other symptoms is documented in the patient record.						
7.2	Response to patient reports of symptom related distress is timely and actions are documented.						
7.3	Care plans accommodate the evolving needs and preferences of the patient and family and whānau.						
7.4	Regular re-evaluation of the effectiveness of treatment is undertaken and includes patient and family and whānau feedback.						

Overall priority rating for standard (circle): High Medium Low

Standard 8:
Caring for patients who are dying

Standard	The unique needs of patients in the last days of life, and the family and whānau, are considered, their comfort maximised and their dignity preserved.
Intent	Health care providers need to be experienced and skilled in recognising when the dying phase of the life limiting condition has begun. This is important in order to facilitate appropriate care for the patient and their family and whānau. The patient and their family and whānau's psychosocial, emotional, cultural and spiritual needs, belief systems and values regarding death and dying are discussed and respected. Evidence shows that lack of open discussion is a real barrier to the delivery of good end of life care.[4] The patient and their family and whānau are assisted to prepare and plan for death by discussing expectations to reduce fear and increase involvement by discussing the dying process and certification processes; and by encouraging them to express their feelings, after death wishes, last wishes and to say their goodbyes. Information, support and plans are in place to avoid inappropriate admissions to hospital.

Chaplin, D. 2009. Developing an end-of-life care pathway to improve nurses' bereavement care. *Nursing Times* Vol105 No1 p 20-21.

Fletcher, C. 1994 Rituals of Grief. Death and Mourning in New Zealand and the Pacific. *New Spirit* Oct p18-21.

[4]Lobb, E. 2006. Suffering, loss, and grief in palliative care. *Australian Family Physician* Vol35 No16 p772-775.

Rogers, J., Niven E. (1996). *Ethics: a guide for New Zealand Nurses*. New Zealand: Longman.

Possible sources of evidence for Standard 8

Evidence source	Quality Element							
Audit/statistical data	**8.1**	**8.2**	**8.3**	**8.4**	**8.5**	**8.6**	**8.7**	**8.8**
Community population demographics								
Patient and family survey	✗	✗		✗		✗		
Staff and volunteer survey	✗	✗						
Environmental survey	✗							
Benchmarking data	✗							
Clinical indicators	✗							
Clinical audit	✗	✗	✗					
Quality improvement project outcomes	✗							
Other sources								
Patient records/assessments	**8.1**	**8.2**	**8.3**	**8.4**	**8.5**	**8.6**	**8.7**	**8.8**
Clinical records review	✗	✗	✗	✗	✗			
Assessment and care planning procedures	✗	✗	✗	✗	✗			
Documentation procedures	✗	✗	✗	✗	✗	✗	✗	✗
Validated tools used	✗	✗		✗				
Other sources	✗							
Business records	**8.1**	**8.2**	**8.3**	**8.4**	**8.5**	**8.6**	**8.7**	**8.8**
Organisation statements (vision, mission, business plan etc)								
Organisation policies and procedures	✗	✗	✗	✗	✗	✗	✗	✗
Review and analysis of clinical incidents					✗			
Review and analysis of complaints	✗							
Review of out of hours contact records					✗			
Access arrangements to community and support services								✗
Minutes of interdisciplinary meetings	✗	✗	✗	✗	✗			
Agreements with external service providers					✗		✗	
Agreements with primary health care providers					✗	✗	✗	✗
Agreements with cultural resource providers	✗					✗		
Induction and other training packages for staff and volunteers	✗							
Training packages for primary caregivers	✗							
Training packages for external health care service providers	✗		✗					
Professional development programmes	✗							
Personnel records								
Records of staff meetings								
Attendance at staff and volunteer education events	✗							
Minutes of committee meetings	✗							
Evidence of formal accreditation								
Formal arrangements with education institutions								
Records of educational events	✗							
Use of standardised national education resources	✗	✗				✗		
Information and resource materials for patients and families	✗	✗		✗		✗		
Other sources	✗							

Recording the results of the assessment of Standard 8

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
8.1	**All palliative care and specialist care service elements** The concerns, hopes, fears and expectations of the imminently dying patient and their family and whānau are discussed openly and honestly in a way that is appropriate for their age, culture, spiritual and social situation.						
8.2	When the patient is assessed as imminently dying the care plan is revised to reflect the needs of the patient and family and whānau and a last days of life care pathway is implemented.						
8.3	The family is educated regarding the signs and symptoms of approaching death, in a way that is appropriate for their age, culture and social situation.						
8.4	Information and discussion on after death wishes and decisions is facilitated, if wanted.						
8.5	Plans are in place for the certification of death, including plans for certification after hours.						
8.6	**Specialist care service elements** There are processes in place to respond to the need for urgent assessment and guidance for all providers caring for patients in the last days of life.						
8.7	Guidance and support is available to health care providers seeking advice about ethical dilemmas related to last days of life care and decision making.						
8.8	Support all providers of palliative care to adopt and implement a last days of life care pathway.						

Overall priority rating for standard (circle): High Medium Low

Standard 9:
Caring for the carer/s

Standard	The carer/s is/are provided with information, support and guidance about their role according to their needs and wishes.
Intent	The primary carer plays a pivotal care coordinating role in the care of the patient, particularly in community contexts where the patient is being cared for at home. Primary carer/s may also have an important role during periods of hospitalisation or inpatient care to continue to provide support and care. The role of primary carer, although often rewarding, can also be stressful. A particular focus on the specific and personal needs of carer/s would allow them to better fulfil their role and reduce the associated stress. This may include support that facilitates effective negotiation where patient, carer/s and/or family and whānau experience conflicting needs. It is acknowledged that the primary carer has individual needs related to support, education, information, loss and grief.[5] Some individuals, families, and whānau may involve different people for advocacy, health and financial decision making.

Possible sources of evidence for Standard 9

Evidence source	Quality Element							
Audit/statistical data	**9.1**	**9.2**	**9.3**	**9.4**	**9.5**	**9.6**	**9.7**	**9.8**
Community population demographics								
Patient and family survey			✘	✘	✘	✘	✘	
Staff and volunteer survey								
Environmental survey								
Benchmarking data								
Clinical indicators								
Clinical audit		✘						
Quality improvement project outcomes								
Other sources			✘	✘		✘		
Patient records/assessments	**9.1**	**9.2**	**9.3**	**9.4**	**9.5**	**9.6**	**9.7**	**9.8**
Clinical records review		✘						
Assessment and care planning procedures		✘		✘				
Documentation procedures								
Validated tools used								
Other sources								
Business records	**9.1**	**9.2**	**9.3**	**9.4**	**9.5**	**9.6**	**9.7**	**9.8**
Organisation statements (vision, mission, business plan etc)								
Organisation policies and procedures								
Review and analysis of clinical incidents							✘	
Review and analysis of complaints				✘		✘		
Review of out of hours contact records							X	
Access arrangements to community and support services								
Minutes of interdisciplinary meetings			✘					
Agreements with external service providers						✘		
Agreements with primary health care providers						✘		
Agreements with cultural resource providers						✘		
Induction and other training packages for staff and volunteers								
Training packages for primary caregivers					✘		✘	✘
Training packages for external health care service providers								✘
Professional development programmes								
Personnel records								
Records of staff meetings								
Attendance at staff and volunteer education events								✘
Minutes of committee meetings								
Evidence of formal accreditation								
Formal arrangements with education institutions								
Records of educational events								
Use of standardised national education resources								
Information and resource materials for patients and families				✘	✘			
Other sources								

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[5] Vachon, M.L.S. (1993), *Emotional problems in palliative medicine: patient, family, and professional*. In Oxford textbook of palliative medicine. 1st edn Doyle, D.Hanks, G. MacDonald, N. Oxford: Oxford University Press.

Recording the results of the assessment of Standard 9

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
9.1	**All palliative care and specialist care service elements** The primary carer/s is/are identified by the patient and their carer/s and family at initial assessment. This is re-confirmed on an ongoing basis.						
9.2	If there is a different carer/s for various elements of care, the different responsibilities of each carer are identified and documented, e.g. financial, spiritual, and cultural.						
9.3	The assessment of carer/s identifies their needs, their desired level of involvement and their ongoing willingness and ability to participate in the provision of care.						
9.4	Carers are provided with up to date information and resources that are adapted to meet their needs and that inform their participation in care planning and delivery.						
9.5	The provision of patient related information to carers is consistent with the consent and wishes expressed by the patient, or previously specified wishes should the patient no longer be capable of providing such consent, and the Privacy Act.						
9.6	Effective networks are established with support services to meet the carer/s needs, including respite care.						
9.7	Carers have adequate support and information to manage emergency and out of hours situations.						
9.8	**Specialist care service elements** Carer education and information resources are developed and available to all palliative care providers.						

Overall priority rating for standard (circle): High Medium Low

Standard 10:
Providing bereavement care

Standard	Formal mechanisms are in place to ensure that the patient and their family and whānau have access to bereavement care, information and support services.
Intent	Emotional and spiritual support focussed on loss and grief includes the patient and their family and whānau and begins when a life limiting condition is diagnosed. Ongoing support based on self identified need is offered to the patient and family and whānau.[6] The majority of people will integrate their loss into their life with the support of their own community. Some people require additional support due to personal circumstances which complicate grief. Bereavement support before and after death of the patient may assist carer/s and family with their loss and grief. Family and carer bereavement support is provided with respect to individuals and their needs within a safe, confidential and ethical approach that is sensitive to the carers' experience, culture and social environment.[7]

Possible sources of evidence for Standard 10

Evidence source	Quality Element					
Audit/statistical data	**10.1**	**10.2**	**10.3**	**10.4**	**10.5**	**10.6**
Community population demographics						
Patient and family survey				x		
Staff and volunteer survey						
Environmental survey						
Benchmarking data						
Clinical indicators						
Clinical audit						
Quality improvement project outcomes						
Other sources						
Patient records/assessments	**10.1**	**10.2**	**10.3**	**10.4**	**10.5**	**10.6**
Clinical records review			x			
Assessment and care planning procedures				x		
Documentation procedures						
Validated tools used			x	x		
Other sources						
Business records	**10.1**	**10.2**	**10.3**	**10.4**	**10.5**	**10.6**
Organisation statements (vision, mission, business plan etc)						
Organisation policies and procedures						
Review and analysis of clinical incidents						
Review and analysis of complaints						
Review of out of hours contact records						
Access arrangements to community and support services		x				
Minutes of interdisciplinary meetings						
Agreements with external service providers			x			x
Agreements with primary health care providers					x	x
Agreements with cultural resource providers						
Induction and other training packages for staff and volunteers						
Training packages for primary caregivers						
Training packages for external health care service providers						
Professional development programmes						
Personnel records						
Records of staff meetings						
Attendance at staff and volunteer education events						
Minutes of committee meetings						
Evidence of formal accreditation						
Formal arrangements with education institutions						
Records of educational events						
Use of standardised national education resources						
Information and resource materials for patients and families						
Other sources						

Beattie, K. (2007). *Walking backwards into your future: coping with grief through continuing bonds*. Dunedin: Rogan McIndoe Print Ltd.

[6] Heaney, P. (2002). *Coming to grief*, New Zealand: Longacre Press.

Hedtke, L., Winslade, J. (2004). *Re-membering lives: conversations with the dying and the bereaved*. New York: Baywood Publishing Company.

[7] Hudson, P., Quinn, K., O'Hanlon, B., Aranda, S. (2010). Clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients. Melbourne: Centre for Palliative Care, St Vincent's Hospital.

Recording the results of the assessment of Standard 10

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
10.1	**All palliative care and specialist care service elements** Appropriate information and resources about loss, grief and the availability of bereavement support services are routinely available to family and whānau before and after the death of the patient.						
10.2	**Specialist care service elements** The service has policies and procedures that guide its bereavement support programme.						
10.3	Families are assessed to identify those at risk of complicated grief and bereavement and referrals to specialist mental health and counselling professionals are made when indicated.						
10.4	The family's need for support is re-assessed on an ongoing basis, including after the death of the patient.						
10.5	The service provides support to all providers of palliative care to identify patients and families who are at risk of complicated grief.						
10.6	The unique bereavement needs of children are provided for with scope to refer to a specialist service for children.						

Overall priority rating for standard (circle): High Medium Low

Standard 11:
Building community capacity

Standard	Community capacity to respond to the needs of people who have a life limiting condition, and their family and whānau is built through effective collaboration and partnerships.
Intent	Good palliative care builds community resilience and reclaims the notion that death is a part of life. Collaborative practice is essential within and between organisations. Recent studies have shown that collaboration encourages the sharing of best practices, challenges and opportunities to improve outcomes for patients and improve workforce satisfaction.[8] Consumers are given an opportunity to contribute to the development of systems and services that meet the requirements of people who have palliative care and bereavement needs. Palliative care services through their knowledge and experience of death, dying and bereavement are an invaluable resource to the community. Community understanding is best served by an awareness that a palliative care approach or service can be provided for people living with a life limiting condition at appropriate times to maximise quality of life and alleviate suffering. Information is available to the community, patients and their familes and whānau in various formats, languages and styles.

Possible sources of evidence for Standard 11

Evidence source	Quality Element								
Audit/statistical data	**11.1**	**11.2**	**11.3**	**11.4**	**11.5**	**11.6**	**11.7**	**11.8**	**11.9**
Community population demographics						✗			
Patient and family survey						✗			
Staff and volunteer survey									
Environmental survey			✗	✗	✗	✗			
Benchmarking data									
Clinical indicators									
Clinical audit									
Quality improvement project outcomes									
Other sources									
Patient records/assessments	**11.1**	**11.2**	**11.3**	**11.4**	**11.5**	**11.6**	**11.7**	**11.8**	**11.9**
Clinical records review									
Assessment and care planning procedures									
Documentation procedures									
Validated tools used									
Other sources									
Business records	**11.1**	**11.2**	**11.3**	**11.4**	**11.5**	**11.6**	**11.7**	**11.8**	**11.9**
Organisation statements (vision, mission, business plan etc)	✗				✗				
Organisation policies and procedures					✗				
Review and analysis of clinical incidents									
Review and analysis of complaints									
Review of out of hours contact records									
Access arrangements to community and support services	✗								
Minutes of interdisciplinary meetings									
Agreements with external service providers				✗					
Agreements with primary health care providers									
Agreements with cultural resource providers				✗					
Induction and other training packages for staff and volunteers									
Training packages for primary caregivers									
Training packages for external health care service providers									
Professional development programmes									
Personnel records									
Records of staff meetings									
Attendance at staff and volunteer education events									
Minutes of committee meetings									
Evidence of formal accreditation									
Formal arrangements with education institutions									
Records of educational events									
Use of standardised national education resources									
Information and resource materials for patients and families									
Other sources									

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[8] World Health Organisation department of Human Resources for Health. (2010). Framework for action on interprofessional education and collaborative practice. Geneva, Author.

Recording the results of the assessment of Standard 11

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		Rating					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
11.1	**All palliative care service elements** Processes for referral to specialist palliative care providers are established.						
11.2	Written information about palliative care services in the region are on display or available for all users of the service.						
11.3	**Specialist care service elements** The service participates in the promotion and support of local and national palliative care awareness initiatives.						
11.4	The service has established links with other service providers and relevant community and government organisations.						
11.5	The service participates in the development and delivery of palliative care education and capacity building initiatives, at a local, regional and national level.						
11.6	The service has mechanisms in place to assess the needs of the community they serve.						
11.7	**Discretionary elements** Advocate for appropriate development of palliative care services for the region.						
11.8	Contribute to national research projects and initiatives on community awareness and improving access to services.						

Overall priority rating for standard (circle): High Medium Low

Standard 12:
Quality and research

Standard	The service is committed to quality improvement and research in clinical and management practices.
Intent	Services are committed to providing the best possible quality of care for people living with a life limiting condition by participating in audit, quality programmes and research projects to meet these goals. Quality management is based on evaluation and continuous improvement principles. Evidence based practice requires the integration of clinical expertise with the best available evidence and patient values. Participation in research will vary based on the capacity of the service and will range from contributing to or facilitating data collection for research, to initiating research projects. Participation in external accreditation programmes assists in development of structured quality improvement programmes, including evaluation of patient care and service outcomes. The service is evaluated from the perspectives of the patient and their family and whānau, health professionals and the community.

Ministry of Health (2002). *Toward clinical excellence: An introduction to clinical audit, peer review, and other clinical practice improvement activities*. Wellington, Author.

Ministry of Health (2003). *The Cancer Control Strategy*. Wellington: Ministry of Health.

Possible sources of evidence for Standard 12

Evidence source	Quality Element						
Audit/statistical data	**12.1**	**12.2**	**12.3**	**12.4**	**12.5**	**12.6**	**12.7**
Community population demographics		✘					
Patient and family survey		✘	✘	✘		✘	
Staff and volunteer survey		✘					
Environmental survey		✘		✘			
Benchmarking data		✘	✘			✘	
Clinical indicators		✘					
Clinical audit		✘	✘	✘			
Quality improvement project outcomes		✘	✘	✘		✘	
Other sources							
Patient records/assessments	**12.1**	**12.2**	**12.3**	**12.4**	**12.5**	**12.6**	**12.7**
Clinical records review		✘	✘				
Assessment and care planning procedures				✘			
Documentation procedures				✘			
Validated tools used			✘				
Other sources							
Business records	**12.1**	**12.2**	**12.3**	**12.4**	**12.5**	**12.6**	**12.7**
Organisation statements (vision, mission, business plan etc)		✘					
Organisation policies and procedures		✘	✘				
Review and analysis of clinical incidents		✘					
Review and analysis of complaints		✘					
Review of out of hours contact records		✘					
Access arrangements to community and support services							
Minutes of interdisciplinary meetings							
Agreements with external service providers							
Agreements with primary health care providers							
Agreements with cultural resource providers				✘			
Induction and other training packages for staff and volunteers							
Training packages for primary caregivers							
Training packages for external health care service providers							
Professional development programmes		✘					
Personnel records		✘					
Records of staff meetings							
Attendance at staff and volunteer education events							
Minutes of committee meetings	✘	✘	✘	✘	✘	✘	✘
Evidence of formal accreditation		✘					
Formal arrangements with education institutions							
Records of educational events		✘					
Use of standardised national education resources							
Information and resource materials for patients and families							
Other sources							

Recording the results of the assessment of Standard 12

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
12.1	**All palliative care and specialist care service elements** Service providers undertake quality improvement activities.						
12.2	Quality improvement activities will demonstrate review and assessment of service delivery and outcomes of care.						
12.3	The clinical practices of the service reflect the integration of evidence based care through robust and rigorous audit.						
12.4	The views of patients and carers are incorporated into quality improvement activities.						
12.5	The service collects accurate data to evaluate and inform service planning.						
12.6	**Specialist care service elements** The service participates in benchmarking processes that support sustainable quality improvement.						
12.7	**Discretionary elements** Research is conducted in collaboration with other specialist care and primary care service providers and academic units.						

Overall priority rating for standard (circle): High Medium Low

Standard 13:
Professional development

Standard	Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.
Intent	All health professionals should demonstrate capabilities in providing a palliative approach to care of patients and their familes and whānau as required. Health professionals involved in the provision of palliative care at any of the resource levels undertake appropriate continuing professional development to ensure that quality care is provided.[9] Volunteers are a large and significant component of the workforce in many services and this needs to be reflected in the systems that guide professional development opportunities. Volunteers are supported to undertake training appropriate to their position.

Possible sources of evidence for Standard 13

Evidence source	Quality Element					
Audit/statistical data	**13.1**	**13.2**	**13.3**	**13.4**	**13.5**	**13.6**
Community population demographics						
Patient and family survey						
Staff and volunteer survey	✘	✘			✘	
Environmental survey						
Benchmarking data						
Clinical indicators						
Clinical audit						
Quality improvement project outcomes						
Other sources						
Patient records/assessments	**13.1**	**13.2**	**13.3**	**13.4**	**13.5**	**13.6**
Clinical records review						
Assessment and care planning procedures						
Documentation procedures						
Validated tools used						
Other sources						
Business records	**13.1**	**13.2**	**13.3**	**13.4**	**13.5**	**13.6**
Organisation statements (vision, mission, business plan etc)					✘	✘
Organisation policies and procedures			✘		✘	✘
Review and analysis of clinical incidents						
Review and analysis of complaints						
Review of out of hours contact records						
Access arrangements to community and support services						
Minutes of interdisciplinary meetings	✘					
Agreements with external service providers						
Agreements with primary health care providers						
Agreements with cultural resource providers						
Induction and other training packages for staff and volunteers	✘	✘		✘	✘	
Training packages for primary caregivers	✘	✘		✘		
Training packages for external health care service providers						
Professional development programmes	✘	✘		✘	✘	
Personnel records	✘	✘	✘	✘	✘	✘
Records of staff meetings						
Attendance at staff and volunteer education events	✘	✘	✘	✘	✘	
Minutes of committee meetings						
Evidence of formal accreditation						
Formal arrangements with education institutions				✘		
Records of educational events	✘	✘	✘	✘	✘	
Use of standardised national education resources						
Information and resource materials for patients and families						
Other sources	✘	✘	✘	✘	✘	

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[9] Wee, B., Huughes, N. (Eds). (2007). *Education in palliative care: building a culture of learning*. Oxford: Oxford University Press.

Recording the results of the assessment of Standard 13

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
13.1	**All palliative care and specialist care service elements** Competency assessment programmes include access to palliative care specific skills and education.						
13.2	An education and training needs assessment is undertaken for staff and volunteers to identify education and training needs.						
13.3	Training and professional development are accessible to staff and volunteers.						
13.4	**Specialist care service elements** The service employs health professionals with the appropriate specialist qualifications and experience (see Hospice NZ website for the hospice capability recommendations).						
13.5	Continuing professional education opportunities incorporating the national standards for palliative care are regularly provided to staff.						
13.6	There is an expressed commitment to the involvement of volunteers, and recognition throughout the service that volunteering is a reciprocal process which benefits volunteers, hospices and communities.						

Overall priority rating for standard (circle): High Medium Low

Standard 14:
Reflective practice and self care

Standard	Staff and volunteers reflect on their practice and maintain effective self care strategies.
Intent	Reflection on practice is a necessary investment in order to improve processes and practices. The provision of care for people with a life limiting condition and their family and whānau can have an emotional and spiritual effect on staff and volunteers. Education about potential effects and possible management strategies need to be provided to maintain sustainable practice and services. Opportunities to reflect upon and express feelings related to interaction with patients and their familes and whānau needs to be part of the palliative care service culture and structure. Staff and volunteers are supported to develop skills for their self care.

Johns, C. (2006). *Engaging reflection in practice: a narrative approach*. Oxford: Blackwell Science.

Johns, C. (2002). *Guided reflection: advancing practice*. Oxford: Blackwell Science.

Possible sources of evidence for Standard 14

Evidence source	**Quality Element**				
Audit/statistical data	**14.1**	**14.2**	**14.3**	**14.4**	**14.5**
Community population demographics					
Patient and family survey					
Staff and volunteer survey	✗			✗	
Environmental survey					
Benchmarking data			✗		
Clinical indicators			✗		
Clinical audit					
Quality improvement project outcomes					
Other sources					
Patient records/assessments	**14.1**	**14.2**	**14.3**	**14.4**	**14.5**
Clinical records review					
Assessment and care planning procedures					
Documentation procedures					
Validated tools used			✗		
Other sources					
Business records	**14.1**	**14.2**	**14.3**	**14.4**	**14.5**
Organisation statements (vision, mission, business plan etc)		✗	✗		
Organisation policies and procedures	✗	✗	✗	✗	✗
Review and analysis of clinical incidents	✗	✗	✗		
Review and analysis of complaints	✗	✗	✗		
Review of out of hours contact records					
Access arrangements to community and support services					
Minutes of interdisciplinary meetings	✗	✗	✗		
Agreements with external service providers		✗			
Agreements with primary health care providers					
Agreements with cultural resource providers					
Induction and other training packages for staff and volunteers	✗		✗	✗	✗
Training packages for primary caregivers					
Training packages for external health care service providers					
Professional development programmes	✗		✗	✗	✗
Personnel records				✗	✗
Records of staff meetings	✗		✗		
Attendance at staff and volunteer education events	✗				✗
Minutes of committee meetings			✗		
Evidence of formal accreditation	✗				✗
Formal arrangements with education institutions				✗	✗
Records of educational events	✗	✗	✗	✗	✗
Use of standardised national education resources		✗	✗	✗	
Information and resource materials for patients and families	✗	✗			
Other sources	✗	✗			✗

Recording the results of the assessment of Standard 14

Quality elements How consistently does your service achieve the following elements of care? What is your evidence? *In determining your assessment for this standard, your team should consider the following quality elements*		**Rating**					Please record your findings and evidence below
		Never	Rarely	Sometimes	Often	Always	
14.1	**All palliative care and specialist care service elements** All staff are educated in reflective practice.						
14.2	Mechanisms for support are identified and used as required, including employee assistance programmes and supervision services.						
14.3	There are procedures in place to identify and respond to critical incidents.						
14.4	There are education programmes in place to enable staff and volunteers to develop effective coping strategies.						
14.5	Supervision and education attendance is encouraged and monitored.						

Overall priority rating for standard (circle): High Medium Low

Hospice New Zealand quality review programme guide

Summary

Once again, we would like to acknowledge the support of Palliative Care Australia (PCA) and the associated National Standards Assessment Program. These resources were instrumental in the overall development of the national standards and quality review programme.

The guideline is available to support services as they work through the quality review programme self review and peer review stages.

The national standards

In 2010, HNZ undertook widespread consultation with the palliative care sector to discuss and inform the revision of the existing national standards (2nd edition, 2001). The development of the 3rd edition national standards is based on the feedback obtained through a consultative process with the wider palliative care sector and the support and information offered by Palliative Care Australia.

Further and ongoing consultation with the palliative care sector, consumers and stakeholders, will ensure that the national standards continue to reflect, as far as possible, the level of care that people of New Zealand can expect when approaching the end of their life.

What is the quality review programme?

The quality review programme is a programme for continuous quality improvement built on the national standards and based on the mutually supportive processes of self and peer review. The core objective of the quality review programme is the improvement of palliative care experiences and outcomes for patients, carers, families and whānau.

A summary of what is involved

It is suggested that services formally assess themselves against the national standards at least every 2 years.

Services are encouraged to align the timing of the self review with audit and accreditation commitments. It is suggested that services undertake a self review six months prior to being audited and include the national standards and quality review programme results, quality action plan and activity information in their pre-audit submissions. This information will demonstrate that the service has well established continuous quality improvement processes, which is a critical component of the accreditation process.

Self assessment is undertaken using a review team. It is recommended that the same team review the evidence of achievement for each standard.

Services will need to:

- establish a review team (ideally 4-7 members)
- identify and collate evidence and data (using audit and clinical indicator data)
- undertake a structured process of review (and agree on appropriate ratings)
- develop an action plan for identified high priority areas for quality improvement
- submit a report of the review results, outcomes and action plan
- participate in the peer review programme within a year of completing the self review

Services will receive a confidential identifiable report which will be useful in prioritising and planning quality improvement actions.

An anonymised report will be produced to provide a national picture of quality improvement opportunities that can be used to support collaboration between services and guide national initiatives.

Overview of the self review

These are the steps a service will need to undertake to complete the review process.

Commit to the framework – self review and peer review components

1. Get support at management level of the service
2. Establish a review team or identify an existing team
3. Notify Hospice New Zealand of start date

Review

4. Convene first review team meeting
5. Create a plan for self assessment
6. Assess against the national standards
7. Record the results
8. Analyse the results for potential areas of improvement

Action plan

9. Develop an action plan
10. Gain support and agreement to invest resources at management levels of the service

By 12 weeks from the start date

11. Report a summary of the results of the self review and action plan using the reporting tool
12. Begin implementing the action plan

Overview of the peer review

Review

1. Notify Hospice New Zealand of desired start date
2. Provide peer review information
3. Plan the peer mentor visit
4. Participate in the peer mentor visit
5. Agree the peer review report

Ongoing – services undertake HNZ QRP review at least every two years

Undertaking the self review

Self review is a mechanism through which organisations can assess current practice, identify opportunities for improvement, develop and implement improvement strategies and monitor and evaluate their outcomes. A 12 week timeframe is allocated for the completion of the self review component of QRP, starting from the date of notification. Any requests for an extension of this time must be directed to Hospice New Zealand.

Steps 1 and 2, and the multidisciplinary team relate to both the self review and the peer review:

Step 1 – Gain commitment and support for QRP at management levels in the service
As a quality improvement initiative, QRP is likely to identify changes required to your current culture, practice or procedures. Such changes require support at management levels of the organisation if they are to be successfully implemented. Clear commitment from management of the service will also assist the team if they arrive at an assessment of performance that is lower than the organisation may have thought. Additionally, management and senior staff must also be willing to undertake the peer review to ensure the self review activities were robust.

Step 2 – Establish a review team to conduct the self assessment
Many organisations will already have a team in place that could undertake the self assessment. This team could be a multidisciplinary team, a quality committee, a mixture of both, or some other team already established. It is recommended that you review the available teams to assess their suitability to conduct the QRP self assessment noting that your team should be drawn from across the organisation and ideally should include the following people:

- Quality manager
- Service manager
- Specialist nursing staff
- Specialist medical practitioner
- Social worker/psychosocial team worker
- Pastoral care/spiritual care worker
- Consumer representative
- Volunteer and/or manager

Steps 3 to 7 are the self assessment stage:

Step 3 – Convene the first review team meeting
Prior to the review team meeting, each member should be provided with a copy of this workbook. All members should understand the self assessment process and steps involved, at the beginning of the first meeting. This meeting should be used to plan the self assessment process. A key task for the first meeting is to identify systems/processes for evidence collection. At this point, the team needs to determine how evidence will be collected and whether there are processes already in place that can be utilised, such as an annual survey or service feedback forms. Many of the evidence sources can be used for more than one standard.

Step 4 – Create a plan for the self assessment
Once the self assessment team has been formed, it should consider how it will undertake the assessment process. This might include the development of a plan that identifies who will undertake key steps such as collection and collation of evidence, a meeting schedule and team responsibilities. How the team organises the assessment will depend on a number of factors such a team member availability, size of service or availability of evidence.

If the whole team is unable to meet regularly alternative processes can be developed, including breaking up into smaller groups to meet or individuals being assigned a standard to work on; however the whole team quality improvement conversations are critical to achieving the best outcomes from the review.

Step 5 – Make an assessment of current achievement for each standard
The national standards set out the conditions and factors which are necessary for the provision of high quality services and establish minimum agreed levels of performance. Working through the national standards using the available evidence, the team should review the service against each standard. The team should arrive at an agreed rating for each quality element and a single overall improvement priority rating for the standard. Determining a rating for a particular standard is a matter of judgement based on analysis of the available evidence by expert, competent and motivated clinicians skilled at assessment.

Step 6 – Record the results of the assessment for each standard

Once the review team has agreed on a rating for each standard, the team should record the results in the results table.

Step 7 – Analyse the results of the self assessment and identify any areas which could be improved

The self assessment process identifies opportunities for improvement. Even where services feel they are performing well against the quality elements they may be able to identify opportunities for improvement.

Steps 8 to 11 occur after the self assessment

Step 8 - Develop an action plan to address any areas where structures, processes or outcomes could be improved

Once the team has identified and prioritised where action to improve current practice is needed, the next step is to develop an action plan to implement those changes. The action plan does not have to address every area for improvement – at a minimum it should address any standard that has been rated as a high priority for quality improvement initiatives.

Step 9 – Gain management support for the action plan

Some of the changes identified through the self review may require management support to ensure changes are implemented successfully, particularly when the action plan identifies changes which have service wide implications or which impact on relationships and agreements with other organisations.

Step 10 – Record a summary of the self assessment and your action plan

A report of the results of the assessment and action plan will be submitted using an online database tool.

Step 11 – Implement your action plan

The service should implement the action plan at this stage.

Step 12 - Proceed to the peer review process

The purpose of the peer review process is to validate the self assessment undertaken by the services. It is not a separate, independent review and assessment process. The peer mentor will work with the self assessment team to review and validate the evidence used in the assessment process and the rating for each standard. The peer mentor will also offer support and guidance on continuous improvement and inform the action plan implementation.

Peer mentors will be appointed by Hospice New Zealand and allocated to undertake peer review visits based on their knowledge and experience. A steering committee and selection criteria will support the selection process.

Waiho i te toipoto, kaua i te toiroa

Let us keep close together, not far apart

Hospice x – how we went about our self review

The following is an example of how one service approached their self review against the national standards.

The CEO and management team started to look at the national standards and quality review programme in April. There was general agreement that our service would commit to undertaking a self review against the standards within the year, aiming for a June start date, to coincide with informing our November certification and accreditation audits. At the same time we committed to participate in the peer review component of the programme within the next 12 months.

We looked at a variety of approaches to forming a self review team, and decided to call for expressions of interest from all staff. Both the quality manager and clinical manager were obliged to be involved, and the CEO agreed to keep a watching brief on our progress. The remainder of the team were representative of most services and functions across all clinical settings. After selection, our team was the quality manager and clinical manager, as already mentioned, a community nurse, the inpatient unit doctor, the psychosocial team leader, the kaiawhina, the volunteer manager, a consumer, and an education team member. Because we are a large hospice, we were tempted to go even wider with our review team, however we considered the advice within the programme guide and kept the team to nine members, which was already a big group. I can only imagine that some small services will have four or five staff in their review teams.

At our first review team meeting, we agreed to schedule a series of meetings across the 12 week timeframe of the self review. We looked at one standard each meeting, although we combined standards 7 and 9, then 13 and 14 into one meeting each to allow us to get through all 14 standards within the timeframe. The meetings were scheduled for two hours each week (we hoped that this amount of time would allow for comprehensive discussion of each quality element and associated evidence) at the same time each week, with the idea that this would become a routine meeting over that time.

If a member of the team was unable to attend they were to find a suitable replacement and brief them on the process. Additionally, at this first review meeting we agreed that the quality manager would have available all the services policies, relevant committee meeting minutes, and recent audit and survey results. Other useful documents would be brought to relevant meetings, or added to the review resources as they were identified.

We had to agree to disagree at times during our discussions, especially when it came time to rating each quality element and similarly with the overall rating for all elements within one standard. How can one group of people who all work around the same patients and families have such differing views of one reality? These quality improvement conversations were the most interesting part of the whole process and it was surprising how many times we came away from these discussions with new understandings of the services we offer, what we do well, and where we could improve. The time spent discussing and debating what and how we meet each quality element was the 'gold' of the self review. The self review team agreed to share this with our teams and peers through various methods in the months following the review.

Then we were ready to submit our results. The reporting database was easy to use, simply going online and inputting the self review results, and a few comments. The report we received back was very interesting, showing our results against an aggregated score of all other services over the past 12 months. The report confirmed most of our quality action plan priorities and made us rethink a few. Where we saw that most services had rated a standard as a high priority we thought we might work with other services, and/or the national office to develop shared quality improvement resources.

We are looking forward to participating in the peer review part of the programme early next year, so that we can talk through and improve our self review process with a peer mentor, but also gain some external expert input into our quality improvement initiatives and our progress to date.

I hope our story is useful to other services before they undertake their own self and peer review. Happy continuous quality improvement.

Quality Manager, Hospice x

Additional resources

The following section has useful information that will support the framework.

Information includes:

Implementing a quality improvement culture

Evidence sources

Audit tools

Developing and implementing an action plan

Peer review information

Resources

Implementing a quality improvement culture

Using a systemic method to work through the stages of improvement cycles ensures that there is a focus on each stage in the sequence, improving the outcomes of efforts to improve quality. The best known quality improvement cycle is the PDSA cycle (Plan-Do-Study-Act), developed by Shewart (1986).
Reference – Shewart, W. (1986). *Statistical method from the viewpoint of quality control*. New York: Dover Publications.

What is PDSA?

Step 1: PLAN
Plan what you are going to do.
Prepare to undertake the self review. Preparation may include a range of activities such as undertaking the organisational readiness assessment, developing a communication strategy for all staff, engaging management to gain their support and commitment. Preparation and planning will also include gathering the evidence and establishing or nominating the multidisciplinary assessment team.

Step 2: DO
Undertake the assessment.
The assessment commences with registration. The review team should assess the quality elements for all standards using the statistical data and other information available to them. This is a process of reflecting on quality of care as a team, specifically with the intention of identifying opportunities for improvement.

The quality review programme provides for a period of 12 weeks for review teams to complete their assessment and submit a summary report of the outcomes. This report will contribute to an anonymised national report of the shared successes and opportunities for improvement identified through the service level assessments. In this way QRP gathers information to support national improvement initiatives as well as local ones.

Step 3: STUDY
What did the assessment reveal?
Analysis of the outcomes of the assessment will help identify areas or aspects of care where opportunities for improvement exist. It will not be possible to address all these opportunities at the same time without placing a considerable drain on existing resources. The self review process requires that the review team provide a recommendation regarding the relative priority of improvement actions for each of the standards. This priority will assist in the development of an achievable and realistic improvement action plan for the organisation. The information from the self review report will be used nationally to better understand the improvement actions that services themselves have identified as important and will be used to inform national quality initiatives that support local action.

Step 4: ACT
Developing an action plan for improvement
It is not enough just to reflect on practice, this is just the first step of an improvement cycle. Developing an action plan based on the prioritised opportunities identified in the assessment phase will ensure that clear goals for improvement are established and acted upon. Most quality review programme activity is undertaken on a 2 year cycle and improvement against these goals can be monitored through successive review phases.

Implementing a quality improvement culture

Improvement is the process of continually working to enhance the experience and outcomes for patients, carers and family/whānau, to find new ways of providing services to meet the needs of those who depend on them and to improve the working lives of the staff that provide care.

To make improvements we must all work to:

- develop ways to involve patients, carers, family, whānau and staff and understand their needs
- develop approaches to measuring outcomes that are meaningful to them as people and as patients
- design safe processes of care to connect these needs and outcomes
- create working environments within which staff and volunteers are provided with opportunities to jointly reflect on, learn and design improvements to the care they provide.

The quality review programme incorporates these requirements into a structured programme to support continuous quality improvement in palliative care. Based on a practical and proven quality improvement tool, the Plan-Do-Study-Act (PDSA) model, QRP is easy to understand and implement in all types of services.

The PDSA model requires teams to establish improvement focused goals, measure changes and decide whether or not they represent an improvement. Services that achieve change are those that value innovation and provide the time and other resources needed to test and learn from experience.

Improvement teams need to involve the right clinical, administrative and management support to make change happen. Senior leaders and upper management will have to establish the team, approve of its goals and create service wide support for the endeavour.

Building a quality improvement culture

The following are the general characteristics that are found in services that adopt a continuous quality improvement (CQI) culture:

- they use problem solving approaches based on statistical analysis and relevant data
- the analytical processes of CQI focus on underlying organisational processes and systems rather than individual performance
- continuous improvement activities use multidisciplinary teams
- employees are empowered to identify problems and opportunities for improved care, and to take necessary action
- there is a focus on internal and external consumers.

Following are some tips on encouraging and building a quality improvement environment within your service:

- harness the energy of clinical teams and create a desire for change to ensure the best care possible is provided to patients, carers and family/whānau
- stop ‘doing to’ and create team ownership for improvement
- make ‘improvement’ a normal part of everyday work

Obtaining management support for quality improvement and QRP

Improvement will not happen without the energy and enthusiasm of frontline staff. We know that. Yet if maximum benefit is to be secured these energies need to be aligned with the strategic aims of the service and community. It is important that services obtain management support before commencing any quality improvement process. This will ensure that a systems leader, with the appropriate level of authority and control over resources, can support the project.

Management support should be obtained from an individual who has the power to authorise the commitment of staff, time and potentially money to complete both the self and peer review and implement the quality improvement action plan.

Evidence sources

A full list of possible evidence sources for each standard is provided with each standard. Evidence can be drawn from a wide variety of documents, information, data and surveys which will need to be available should you choose to proceed to peer review.

Statistical data and other primary sources of evidence should be incorporated wherever possible as they provide the strongest evidence of performance against a standard. It is important that wherever possible feedback from patients and their families is also included as evidence to support assessment.

Evidence collected for accreditation programmes can be used for QRP and similarly, evidence collected during the review process can be used for accreditation purposes.

There are many potential evidence sources available to undertake and support the self assessment process. Evidence can be primary or secondary:

- primary sources of evidence are those where the data or information is gathered directly from the process or source, for example administrative data (patient age, sex, length of stay) or patient or family survey or clinical audit data.
- secondary sources of information include indirect evidence, for example policies and procedures, mission statements etc which do not necessarily indicate what has actually occurred but rather point to what should have occurred.

Primary sources of evidence are much stronger indications of actual care processes and outcomes. Statistical data and other primary sources of evidence should be used when possible as this strengthens the self assessment process by incorporating objective measures of outcomes or processes.

Where statistical data or primary evidence does not exist secondary sources of evidence (for example policies and procedures, guidelines etc) can be used but the level of confidence for the self assessment rating will be lower than if a primary evidence source was available.

A list of possible evidence sources for each standard is provided in a table alongside each standard. While the table is designed to be as comprehensive as possible, it is not necessarily exhaustive. Services may have other sources of evidence that they believe are valuable for assessing achievement against the national standards. If there is other evidence, serivces should ensure that it is used to help undertake the assessment and support the ratings allocated against each standard.

Peer reviewers will request access to the evidence as part of the process of validating the self assessed rating.

Use of all of the evidence sources is also not mandatory – we recognise that services are all different and that some will not have all of the types of evidence included in the list.

Audit tools

Data collection using audit tools

The quality review programme recommends using audit tools on a regular basis to provide your service with information about its processes and, importantly, the outcomes for patients, families and whānau. There are numerous tools available for services to collect audit data, including benchmarking tools and clinical audit tools.

Importance of audits

Conducting regular audits provides services with information about the service's processes and, importantly, the outcomes for patients, families and whānau. Evidence of performance against the national standards can be collected and assessed in a number of ways. Audits can help provide this evidence. For example, an audit of patient records can help provide evidence for standard 6 of patient involvement in care planning.

Choosing an assessment or audit tool

There are a number of tools available to the palliative care sector to assess patients and collect audit data. The following outlines some of the areas where a tool could be used:

- advance care planning
- caregiver well being
- continuity of care
- emotional symptoms
- last days of life care
- functional status
- grief and bereavement
- physical symptoms
- psychological
- quality of life
- satisfaction
- sense of wellbeing
- spirituality

Issues to consider when choosing a tool

Every survey tool has its own advantages. The tool chosen will depend on several factors, some of which are likely to be specific to a service. When feasible, patients should be directly surveyed about the quality of their care. However, some patients may not be able to complete an interview, due in part to short length of stay with palliative care services or their physical condition.

When interviewers are trained and sensitive to bereavement issues both patients and family members are usually very willing to participate in surveys of this type. Interviewing patients and family members requires a conceptual shift to focus not on what went well (i.e. level of satisfaction), but on asking the patient and family to identify areas in need of improvement. Overcoming the tendency of patients and families to be lenient in their service evaluations is done by asking them to more clearly define their experience in terms of the quantity and quality of important aspects of that care.

Developing a quality improvement action plan for the national standards

Developing a quality improvement action plan related to those standards where there is scope for performance improvement is the most important part of the quality review programme. It ensures that the framework is part of a cycle of continuous quality improvement, not a one off review and reporting activity.

The key components of an action plan are:

1. a statement of the goals for improvement and the expected outcomes
2. detailed steps of what must be done to achieve the desired outcome
3. a schedule for each step and how long it is likely to take
4. indication of who will be responsible for making sure each step is completed
5. clarification of the resources required.

Action planning is a challenge because it involves translating abstract concepts and ideas into specific tasks and activities for execution. It requires that roles, timelines and deadlines be clearly established. All of these require negotiation, mediation and dedicated resources – and this is particularly difficult in palliative care where there are many stakeholders, and where resources can be scarce and precious commodities.

Quality improvement action plans need to be aligned with the strategic and operational plans of the organisation to ensure that they are seen to add value and are supported and successfully implemented. One of the challenges that many organisations face is random improvement and management activities disconnected from the priorities of the organisation.

Essentials of action planning

1. Consider the constraints and opportunities within your environment. Context is important when planning for action.
2. Agree on the priorities that arise through the review process and assure that all involved share a common understanding of the rationale behind the prioritisation process.
3. Understand the five critical steps of action planning: know what you are trying to achieve, define the steps, and know who is responsible for each step. Define a schedule and understand the resources you have to work with.

Smart action planning

It is worth remembering SMART actions:

Specific – define what exactly is to be done
Measurable – describe how you will know the action has been achieved
Achievable – set realistic plans
Relevant – relate the actions to ongoing work
Time bound – set a date for completion

Action planning – step by step guide

The following describes the key steps a service will need to take to develop an action plan based on the self review. A template is attached for a palliative care quality improvement action plan. You may choose to use this action plan or use another plan that your service is more familiar with. Either way the steps of action planning are essentially the same.

Step One: Prioritising the outcomes of the QRP self review

The QRP self assessment process identifies opportunities for improvement linked to the national standards. The self assessment process requires that the review team determine a priority rating for each standard after reviewing the quality elements. Even so, there may be more priority areas for improvement than can be reasonably managed. The following are some criteria you may like to consider to decide which improvement opportunities should be included in the action plan:

- improvements that are required to ensure compliance with regulatory or legislative standards or requirements
- improvements that will be of most benefit to patients, caregiver/s and family and whānau
- improvement actions that will have a positive impact on a number of identified opportunity areas
- improvements that staff and managers will be most supportive of
- improvements that are most likely to succeed.

Step Two: Documenting the improvement plan

This step involves the development of the improvement action plan. This involves setting the improvement goal, identifying the specific improvement actions, assigning responsibility for the actions, identifying the timeline and determining how results will be monitored and improvement demonstrated.

Goal

The improvement goal should be achievable, measurable and clearly linked to the improvement opportunity. The goal should also be linked to desired improvements in the assessment rating and if appropriate other benchmarks.

Improvement actions

The improvement action needs to be expressed in sufficient detail to provide a roadmap that will translate aspirations for improving quality into practical and achievable results. What are the key tasks that need to be accomplished to achieve the goal? The improvement opportunity may need to be broken down into smaller parts until you can identify the tasks that will lead to achieving the goal. These should be recorded on the action plan.

Responsibility

Think about each major task and the skills that are required to accomplish each. Avoid jumping immediately to assign responsibility to an individual person. You need to ensure that the task that needs to be accomplished is covered. Identify all the appropriate people in the organisation with these skills who can assist with implementing the quality improvement action plan to assist with sharing the load. Experience is more important than title as long as the plan has buy in from leadership.

Timeline

Milestones are important communication tools as your plan is implemented. Milestones identify progress towards your ultimate goal and are useful to those leading the improvement actions, the team involved in the implementation as well as management.

Monitoring the results

For quality improvement projects, data should be monitored at least quarterly and where possible monthly. It is recommended that the data be considered at least monthly at one of the service's multidisciplinary team meetings. Using the data real time to guide your improvement plan will accelerate change and assist you to reach your improvement goals more quickly. Results should be communicated with management and other key stakeholders as appropriate.

Aroha atu, aroha mai

given with love, received with love

Quality improvement action plan – template

Standard number ________ **Overall priority rating** ____________________________ **Date** ______________

Outcome of assessment			Improvement strategy					Evaluation		
No.	Quality elements requiring improvement	Current rating	Desired rating	Improvement action	Responsible party/parties	Due date	How results will be monitored	Actual date of completion	Rating on completion	Follow up tasks

Quality improvement action plan – example

Standard number 6 **Overall priority rating** High **Date** 26/06/12

Outcome of assessment			Improvement strategy					Evaluation		
No.	Quality elements requiring improvement	Current rating	Desired rating	Improvement action	Responsible party/parties	Due date	How results will be monitored	Actual date of completion	Rating on completion	Follow up tasks
6.1	The patient's care plan takes into consideration the patient, family and whānau description of their experience and needs	Rarely	Often	Review existing admission and care planning forms and processes to incorporate patient and family experience and needs	Clinical nurse manager	26/07/11	Audit charts to ensure completion	02/08/11	Sometimes	Repeat action cycle for another month
6.6	The patient and their family and whānau are provided with up to date and appropriate information to meet their needs and support their participation in care planning and decision making	Never	Often	1. Update resources 2. Ensure all patients and carer/s receive information on admission	Service manager and clinical nurse manager	30/08/11	3. Evaluate revised resources 4. Survey patients and carer/s			

Peer review information

The peer review programme will become an important, and possibly compulsory, component of the quality review programme. Peer mentors will carry out an important role in mentoring services to support continuous improvement, by:

- reviewing and validating a services self assessment against the national standards
- providing support and guidance to a service regarding their improvement action plan
- facilitating access to appropriate evidence, information and networking.

Peer review process

Services participate in the peer review programme within 12 months of completing their self assessment. This gives the service time to review the aggregated self assessment results and make any necessary adjustments to their improvement action plan. It also gives the service time to construct a detailed plan and begin implementing the improvement actions.

Peer mentors will be appointed by Hospice New Zealand and allocated to undertake peer review visits based on their knowledge and experience. A steering committee and selection criteria will support the selection process.

Peer mentors will need to meet recruitment criteria, comply with a code of conduct, observe privacy requirements and mentor services using the peer review programme materials and processes.

Peer review materials

Peer mentors will receive training, using a peer mentor training manual. Pre-meeting briefing information will be provided by both Hospice New Zealand and the service under review. The peer mentor visit will be documented using a peer mentor visit workbook.

The peer review report will be provided to the service undertaking the review and agreed to by both parties.

Resources

Hospice New Zealand has access to resources from hospices and other palliative care services who have offered their information for others to use.

Hospice New Zealand will continue to develop the resource page on our website, which will be kept up to date, with links to the latest versions of these resources. New resources will be added, with the permission of the provider, as they become available.

Some of the resources available on the Hospice New Zealand website include –

The Palliative Care Handbook

Validated assessment tools

Clinical guidelines

Patient, family and whānau information pamphlets

Hospice capability recommendations

The Palliative Care Glossary

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Introduction

This Palliative Care Glossary is intended to be the beginning of a process to develop a common understanding of terms used in palliative care in New Zealand. To date, many of the terms defined in this glossary have held various meanings resulting in inconsistent use and confusion.

The Palliative Care Council of New Zealand, Hospice New Zealand and the Ministry of Health have all been involved in developing this Glossary. These organisations have agreed to use the terms and associated descriptions contained in the Glossary in all future documentation and correspondence.

The Glossary will require ongoing review and refinement to ensure it remains up-to-date and is consistent with agreed usage of the terms it contains. Where possible, terms will reflect international definitions to assist with international sharing and collaboration. This also reflects the fact that documents are made available on the internet and so are accessible to an international audience.

Feedback and contributions to the Glossary are welcomed as part of the ongoing development and review. Please send any comments or suggestions to info@palliativecarecouncil.govt.nz, or contact the Palliative Care Council of New Zealand on (04) 815 9800.

A

Advance Directive: Instructions that consent to, or refuse, specified medical treatment or procedure in the future.

Advance directives are defined in the Code of Health and Disability Services Consumers' Rights (the Code) as written or oral directives in which the patient makes a choice about a possible future health care procedure, and this choice is intended to be effective only when the patient is no longer competent. For this reason, advance directives are also, though less frequently, referred to as 'living wills'.

Right 7(5) of the Code gives every consumer the legal right to use an advance directive in accordance with common law.

Advance Care Plan: An advance care plan is the desired outcome of the Advance Care Planning process. An advance care plan is an articulation of wishes, preferences, values and goals relevant to all current and future care. It is not intended to be used only to direct future medical treatments and procedures when the person loses capacity to make their own decisions (becomes incompetent).[ii]

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.[ii]

Advance Care Planning (ACP): Advance Care Planning (ACP) is a process of discussion and shared planning for future health care. It is focused on the individual and involves both the person and the health care professionals responsible for their care. It may also involve the person's family and whānau and/or carers if that is the person's wish. ACP 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.[ii]

Allow Natural Death (AND): Allow natural death means not interfering with the natural dying process, while at the same time providing care directed at keeping the patient as comfortable as possible. The term 'allow natural death' may be used as an alternative to 'Do Not Attempt Cardio-Pulmonary Resuscitation' (DNACPR).

A decision to allow natural death does not indicate a withdrawal of care, although it may include withholding or discontinuing resuscitation, artificial feedings, fluids, and other measures that would prolong a natural death. In addition to agreed interventions, the patient will continue to receive:

- Prompt assessment and management of pain and other distressing symptoms
- Other comfort measures including emotional, cultural and spiritual support
- Privacy and respect for the dignity and humanity of the child and their family
- Management of hydration and nutrition needs as appropriate to the circumstances
- Oral and body hygiene.

B

Bereavement: The period after a loss during which grief is experienced and mourning occurs. Although there are similarities in people's responses, there are also marked differences. Each person will grieve and recover in their own way and in their own time.

C

Care Pathway: A care pathway is a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period. Defining characteristics of care pathways include:

(i) an explicit statement of the goals and key elements of care based on evidence, best practice, and patients' expectations and their characteristics;
(ii) the facilitation of the communication among the team members and with patients and families;
(iii) the coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, patients and their relatives;
(iv) the documentation, monitoring, and evaluation of variances and outcomes; and
(v) the identification of the appropriate resources. The aim of a care pathway is to enhance the quality of care across the continuum by improving risk-adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimizing the use of resources.

Cardio-Pulmonary Resuscitation (CPR):
Cardiopulmonary resuscitation (CPR) is a procedure used when a patient's heart stops beating and breathing stops. It can involve compressions of the chest or electrical shocks along with rescue breathing. CPR includes a number of treatment options including:

- rescue breathing
- cardiac compression
- tracheal intubation
- electrical cardioversion
- resuscitation medication.[±]

Note: Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) is an order specifically requesting that the above interventions are not attempted (see Allow Natural Death).

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.

[Note: this Glossary proposes to not use the term ‘illness’, as it implies a more narrow scope of health issues that impact on a person’s quality of life.]

D

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

Dying: A person is considered to be dying when they are in the process of passing from life to death.vii It is characterised by a gradual failing of vital functions including the cardiac, respiratory and central nervous systems, followed by an absence of criteria that define life (spontaneous heartbeat, breathing and brain function). The dying phase is generally considered to be minutes to hours in duration, but can occasionally be just seconds.

E

End of Life: The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the patient, but it is often the patient or family who first recognises its beginning.

End of Life Care: End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family and whānau during the end of life phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family and whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family.[viii]
End of Life Care Plan: An end of life care plan can be used instead of a Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) order, to ensure that people with a life-limiting or life-threatening condition have a clear plan in place for end of life care.

See also: Te Wā Aroha.

Enduring Power of Attorney (EPA): An authority given by a patient, while they are competent, to another person, in order for that person to act for the welfare of the patient only once the patient is mentally incompetent. Under new legislation (2007), a medical certificate that the patient is mentally incapable is required before a person with an EPA can act in respect of certain matters. Note there are two types of EPA: ‘property’ and ‘personal care and welfare’.[ii]

F

Family: A family is defined as those who are closest to the patient 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).[v]
See also Whānau.

G

Generalist Palliative Care: Refer to ‘Primary Palliative Care’.

[Note: this Glossary proposes not to use the term ‘Generalist Palliative Care’, as it does not adequately describe the nature of palliative care provided by health services that are not specialist palliative care services.]

H

Holistic: A system of comprehensive or total patient care that considers the physical, emotional, social, economic, and spiritual needs of the person; their response to illness or life-limiting/life-threatening condition; and the effect of the illness or condition on the 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: Hospice is not only a building; it is a philosophy of care. 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 and supportive care.

Hospices provide care for the whole person, not just their physical needs but also their emotional, spiritual, and social needs. They also care for families and friends, both before and after a death. Irrespective of where a hospice service is, this philosophy of care does not change. In New Zealand all aspects of hospice care are provided free of charge.

I - J

Interdisciplinary Team: A group of individuals with diverse training and backgrounds who work together as an identified unit or system. Team members consistently collaborate to solve patient problems that are too complex to be solved by one discipline or many disciplines in sequence.

Membership varies depending on the services required to identify and address the expectations and needs of the patient, caregiver and family. A palliative care interdisciplinary team typically includes one or more doctors, nurses, social workers, spiritual advisers, pharmacists, and personal care workers. Other disciplines will be part of the team as resources permit.[v]

K - L

Life-Limiting Condition: A life-limiting condition is one for which there is no reasonable hope of cure and from which the person will die. Some of these conditions cause progressive deterioration rendering the person increasingly dependent on family and carers.[viii]

Also refer to ‘Life-threatening condition’ and ‘Terminal condition’.

[Note: this Glossary proposes to not use the term ‘illness’, as it implies a more narrow scope of health issues that impact on a person’s quality of life.]

Life-Threatening Condition: Life-threatening conditions are those for which curative treatment may be feasible but can fail.viii 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.

Also refer to ‘Life-limiting condition’ and ‘Terminal condition’.

[Note: this Glossary proposes to not use the term ‘illness’, as it implies a more narrow scope of health issues that impact on a person’s quality of life.]

Liverpool Care Pathway (LCP): The LCP is an evidence-based, integrated care pathway that was developed to transfer the hospice model of care into other care settings. The LCP guides health care professionals to deliver best practice care to dying patients and their families and whānau in the last days and hours of life, irrespective of diagnosis or care setting.

M - N

Multidisciplinary Team: A multidisciplinary team consists of a team of professionals, including representatives of different disciplines, who coordinate the contributions of each profession, which are not considered to overlap, in order to improve patient care.

Members of a multidisciplinary team might include GPs, surgeons, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, occupational therapists, physiotherapists, dieticians, volunteers, pharmacists or care assistants.[v]

O - P

Paediatric Palliative Care (PPC): The World Health Organization (WHO) definition of palliative care for children defines paediatric palliative care as “a special, albeit closely related field to adult palliative care”. WHO’s definition of palliative care appropriate for children and their families is as follows (the principles also apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child’s body, mind and spirit, and also involves support for the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child’s physical, psychosocial, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources. It can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children’s homes.

Palliation: To palliate is to alleviate a symptom without curing the underlying medical condition or pathological process. 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.[v]

The aim of palliation is to help a patient feel more comfortable, and it improves quality of life but does not cure the disease. Palliation of symptoms is a key goal of care for both end of life and palliative care.

Palliative Approach: A palliative approach embraces the World Health Organization definition of palliative care. It incorporates a positive and open attitude toward death and dying by all service providers working with patients and their families, and respects the wishes of patients in relation to their treatment and care.

Palliative Care: The World Health Organization defines palliative care as: an approach that improves the quality of life of patients and their families facing the problems associated with life-limiting or life-threatening conditions, 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 nor 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.

A New Zealand specific definition of palliative care is

Care for people of all ages with a life-limiting or life-threatening condition which aims to:

1. Optimise an individual's quality of life until death by addressing the person's physical, psychosocial, spiritual and cultural needs.
2. 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 may be.

It should be provided by all heath 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. These include Māori, children and young people, immigrants, refugees, and those in isolated communities. Palliative Care Services: This term refers to any individual, team or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team.

Palliative Care System: This refers to 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. Without these 'other factors' palliative care providers cannot function as part of a 'system'.

It is not simply the existence of primary palliative care providers and palliative care services that comprises the palliative care system; it is the links that exist between them that tie together 'a system'. An Interdisciplinary Team approach to palliative care is one example of how such links can be developed and maintained.

Patient: A patient is the primary recipient of care. In the practice of palliative care, the patient together with their family and carers are the focus of care.[v]

Primary Carer: The primary carer is generally in the close kin network of the patient and is usually self identified. The primary carer can be the patient's spouse, child, another relative, family member or friend. They may be supported by other carers, but generally will take a primary role in the co-ordination and delivery of care and support to the patient. This person provides for the practical needs of the patient and takes on additional tasks that may be of a technical nature, to provide ongoing care for the patient, e.g. the administration of medications. They provide the primary support role for the patient at all levels of need.[v]

Primary Palliative Care: Primary palliative care is provided by all individuals and organisations that deliver palliative care as a component of their service, but their substantive work is not in the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any healthcare professional who is not part of a specialist palliative care team.

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

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient's needs exceed their services capability.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of all people.

[Note: this Glossary proposes not to use the term 'Generalist Palliative Care', as it does not adequately describe the nature of palliative care provided by health services that are not specialist palliative care services.]

Q, R, S

Specialist Palliative Care: 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 patients have access to at least medical and nursing palliative care specialists.[xvii]

Specialist palliative care is delivered in two key ways in accordance with New Zealand Definition of Palliative Care.

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

Standards: A standard is something established as a measure or model to which other similar things should conform. There are three types of standards in health care: structure, process, and outcome standards. Structure refers to evaluation of the setting in which care is rendered and the resources that are available. Process refers to evaluation of the actual activities carried out by the care giver. Outcome refers to evaluation of the results of activities in which the nurse has been involved (what the result is for the patient).[xiii]

For example: the Hospice New Zealand Standards set out best practice in relation to the provision of end of life care in hospices. They identify the essential elements that need to be in place to ensure consistent quality end of life care across the hospice sector.[xv]

Supportive Care: Supportive care helps the patient and their family / whānau to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease.

When the underlying disease has been identified as incurable, 'Supportive Care' would be best substituted with 'Palliative Care'.

T, U, V

Te Wā Aroha: Te Wa Aroha is the title in Te Reo Māori given to the Starship Children's Hospital end of life care plan. Te Wā Aroha translates as 'a time of love' or 'time of compassion'.

See: End of Life Care Plan.

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.[v]

Also refer to 'Life-limiting condition' and 'Life-threatening condition'.

[Note: this Glossary proposes to not use the term 'illness', as it implies a more narrow scope of health issues that impact on a person's quality of life.]

W, X, Y, Z

Whānau: Whānau means the 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.

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Hospice New Zealand additional glossary terms specific to the national standards and quality review programme

Audit: Healthcare audit is an audit of current practice against standards in any aspect of healthcare and includes both clinical and non-clinical audit.

Care plan: A plan, based on an interdisciplinary assessment, carried out by a team of health professionals in collaboration with the patient and their family and whānau. It has four essential components: identification of the issues or problems and statement of the care approach to solve those problems; statement of the expected benefit to the patient; statement of the specific actions by the team that reflect the care approach to achieve the goals specified; and evaluation of the patient's response to the intervention and readjustment of that care as required. The care plan is begun when the patient is admitted to the service, and, after the initial assessment, a diagnosis is formulated and a care plan is developed. The goal of the process is to ensure that care is consistent with the patient's needs. A written care plan should be a part of every patient's notes.

Care setting: All locations where care is delivered are included in this definition. Clinical teams have a responsibility to work with patients, family, whānau and other health care providers to negotiate an appropriate and safe environment for the patient and their family and whānau, and staff.

Collaboration: Collaborative practice in health care occurs when multiple health workers from different professional backgrounds provide comprehensive services by working with patients, their families, carers and communities to deliver the highest quality of care across settings (WHO 2010).

Critical incident: Critical incidents are snapshots of something that happens to a patient, their carer, family, whānau or a health care provider. It may be something positive, or it could be a situation where someone has suffered in some way (Rich and Parker 2001). They are a valuable learning tool.

Cultural supervision: The Māori supervisee will reflect and increase professional capability around Māori cultural specific aspects of their work with Māori. Cultural supervision is also relevant to other ethnicity supervisees around culturally specific aspects of their work with same ethnicity patients and families.

Decisional capacity: In order for a patient to be autonomous or to make competent decisions in their own interest, they must be fully informed of the facts and probabilities, able to understand, able to make a voluntary and reasoned choice and be able to communicate that choice.

Ethnicity: Ethnicity is the ethnic group or groups that people identify with or feel they belong to. Ethnicity is a measure of cultural affiliation, as opposed to race, ancestry, nationality or citizenship. Ethnicity is self perceived and people can belong to more than one ethnic group. Race is a biological indicator and an ascribed attribute. Ancestry is a biological and historical concept and refers to a person's blood descent. Citizenship is a legal status. These terms contrast with ethnicity which is self–perceived and a cultural concept. *http://www.stats.govt.nz/surveys_and_methods/methods/classifications-and-standards/classification-related-stats-standards/ethnicity/definition.aspx#definition*

Evaluation: Evaluation is defined as assessment/appraisal of the degree of success in meeting the goals and expected results (outcomes) of the organisation, service, programme, population or patients.

Evidence: Evidence based medicine came to the fore in the early 1990s and has become a major driving force for many national healthcare organisations. The term and concept originated at McMaster University. It has been defined as "the integration of best research evidence with clinical expertise and patient values" (Sackett, 2000). *http://www.openclinical.org/guidelines.html*

Guidelines: A guideline is defined as a principle or criterion that guides or directs action (Concise Oxford Dictionary 1995). Guidelines are designed to support the decision making process in patient care. The content of a guideline is based on a systematic review of clinical evidence - the main source for evidence based care. *http://www.openclinical.org/guidelines.html*

Imminently dying: The last days to hours of a person's life. Death is imminent and the goals of care should be focused on comfort and dignity.

Policies: A policy is a written statement that clearly indicates the position and values of the organisation on a given subject.

Procedures: A procedure is a written set of instructions that describe the approved and recommended steps for a particular act or sequence of events.

Protocols: A protocol is defined as a written plan that specifies procedures to be followed in defined situations; a protocol represents a standard of care that describes an intervention or set of interventions. Protocols are more explicit and specific in their detail than guidelines; they specify who does what, when and how. Protocols are most typically used when developing instructions, for example drug prescription, dispensing and administration.

Proxy: a person authorised to act on behalf of another. Respite: Caring for a friend or family member can be demanding so when carers need a break funding systems are available to provide care in a care facility for their loved one.

Spirituality: Spirituality means different things to different people. It may include (a search for): one's ultimate beliefs and values; a sense of meaning and purpose in life; a sense of connectedness; identity and awareness; and for some people, religion. It may be understood at an individual or population level (Egan, et al., 2011).

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Rārangi maunga, tā tonu, tā tonu.
Rārangi tangata, ngaro noa, ngaro noa

You have gone –
but your mountain is everlasting