

New Zealand Palliative Care Glossary

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Palliative Care Council of New Zealand

The Palliative Care Council was established in 2008 by Cancer Control New Zealand to provide independent and expert advice to the Minister of Health and to report on New Zealand's performance in providing palliative and end of life care. Cancer Control New Zealand and the Palliative Care Council was disestablished on 8 August 2015 by the Minister of Health.

The Palliative Care Council included representatives from the New Zealand Branch of the Australian and New Zealand Society of Palliative Medicine, Hospice New Zealand, Hospital Palliative Care New Zealand and Palliative Care Nurses New Zealand, and members nominated by the Royal NZ College of GPs/NZ Rural GP network, Nursing Council of NZ, Māori and consumers.

The New Zealand Palliative Care Glossary is now the responsibility of the Ministry of Health.

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Introduction

The first New Zealand Palliative Care Glossary was prepared by the Palliative Care Council and published jointly with Hospice New Zealand and the Ministry of Health in January 2012. The introduction to that glossary (Palliative Care Council 2012) said:

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.

It was found during the process to update the glossary that definitions have become more contentious in recent years and that practice has evolved differently in different countries and different medical specialities. The lack of international clarity gives us an added incentive to revise the Glossary specifically for the New Zealand context. We invite others around the world to reflect on the terms and adapt our work to their own countries, while working to advance common international terminology in palliative care.

The New Zealand Palliative Care Glossary has not previously contained any diagrams and glossaries are typically definitions of terms using only words. In the interests of greater clarity of understanding, a number of key diagrams have been added in this edition. More extensive footnotes also give background to the decisions to use some particular terms. Finally, we have refreshed the language from the 2012 edition, shortening and making the definitions more direct where possible.

As the Palliative Care Council was disestablished on 8 August 2015, the Glossary is now the responsibility of the Ministry of Health.

Feedback and contributions to the revised glossary are welcomed as part of the ongoing development and review of this living document. Kindly contact the Ministry of Health at cancerteam@moh.govt.nz.

A

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

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

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

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

Advance Directive: consent or refusal to specific treatment(s) which may be offered in the future when the person no longer has capacity.

Right 7(5) of the Code of Health and Disability Services Consumers' Rights (Palliative Care Council 2012) gives every consumer the legal right to use an advance directive in accordance with common law. The advance directive may be written or oral.

Allow Natural Death (AND): is an instruction written for other healthcare providers that allows a natural course of events to occur in an acute care setting (Paediatric Palliative Care Coalition 2015). The term Allow Natural Death may be used as an alternative to Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR), or Do Not Resuscitate (DNR).

It is an active, positive position embodying the hope that dying will occur peacefully and naturally as possible, surrounded by loved ones. Allow Natural Death codifies the spirit of ongoing communication between the person and legal decision-maker(s) and the health care team. Its completion should not be viewed as an end in itself, but rather as a tool to document preferences while facilitating further advanced care planning (Paediatric Palliative Care Coalition 2015).

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 person 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 person and their family/whānau
- management of hydration and nutrition needs as appropriate
- oral and body hygiene.

Ārai (o te mate): veil, curtain (of death)

Ko te wehenga i waenga i te ora me te mate.
The separation between life and death.

Hei Tauira Kōrero (examples):

- Whakatau mai rā koutou ki a ia kua whakawhiti nei i te ārai, ki ngā ringa o tō tātou Matua i te rangi.
Welcome to you all in acknowledgement of him/her who has crossed the veil, into the hands of our Father in heaven.
- Haere e te taonga a Mate, haere ki tua o te ārai.
Farewell dear treasure of Death, make your journey to beyond the veil Privacy and respect for the dignity and humanity of the person and their family/whānau.

Atua: ancestor with continuing influence, supernatural being, deity, often translated as God (Moorfield 2015).¹

B

Bereavement: the period of grief and mourning after a death. It is part of the normal process of reacting to a loss.

Grief may be experienced as a mental, physical, social or emotional reaction. Mental reactions can include anger, guilt, anxiety, sadness and despair. Physical reactions can include sleeping problems, changes in appetite, physical problems or illness (US National Library of Medicine 2015).

C

Cardio-Pulmonary Resuscitation (CPR): is an emergency procedure used when a person's breathing or heartbeat has stopped. CPR combines rescue breathing and chest compressions, where rescue breathing provides oxygen to the person's lungs and chest compressions keep oxygen-rich blood flowing until the heartbeat and breathing can be restored (Hazinski et al 2010). Other procedures used may tracheal intubation, electrical cardioversion or resuscitation medication.

Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) is an order specifically requesting that the above interventions are not attempted. See also 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.²

Serious and persistent chronic conditions are multidimensional, interdependent, complex and ongoing (Palliative Care Australia 2005). Chronic conditions are characterised by persistent and recurring health consequences lasting for three months or more.

¹ This is an edited version of the full dictionary description.

² The term 'illness' is not used as it implies a more narrow scope of health issues that impact on a person's quality of life.

See also Long-term Condition.³

D

Death: the cessation of all vital functions of the body, including the heartbeat, breathing and brain activity (including the brain stem) (Palliative Care Australia 2005).

Dying: a person is considered to be dying when they are in the process of passing from life to death (Palliative Care Australia 2005).

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. It may also be days in duration, where the loss of function indicates death is imminent.

See also Last Days of Life.

E

End of Life: is that period of time prior to death but the duration can never be precisely defined in advance (National Gold Standards Framework Centre 2011).⁴

Recognising and identifying those people who are at risk of dying at some point in the year ahead enables the health and social systems to respond to the deteriorating person and their families/whānau/carers in a holistic and comprehensive way.

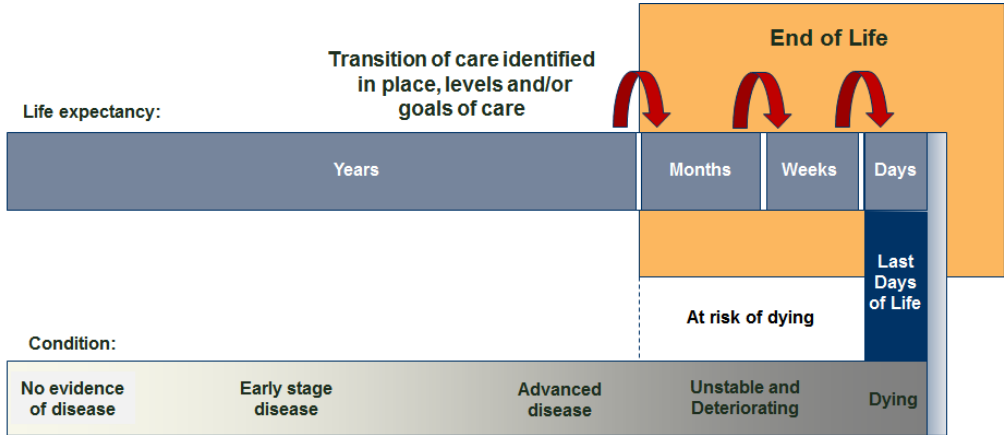
Although prognostication is inherently difficult, being better able to predict when people are reaching the end of life phase, whatever their diagnosis, makes it more likely that they receive well-coordinated, high quality care. This is more about the health care system meeting needs than giving defined timescales. The focus is on anticipating the needs of the person and families/whānau/carers so that the right care can be provided at the right time. This is more important than working out the exact time remaining and leads to better proactive care in alignment with preferences.

The end of life period is triggered by a transition in the place of care, levels of care and/or goals of care. The major transition to the end of life period is in changing the focus on the person from curative and restorative care, which aims to extend the quantity of life, to palliative care which aims to improve the quality of life.

³ In New Zealand the terminology 'long-term condition' is increasingly used, rather than 'chronic condition'.

⁴ The wording has been adapted from the Gold Standards Framework.

Figure 1: End of life and last days of life⁵



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

Planning for coordinated end of life care across all levels of the health system is essential for District Health Boards. Tools such as the Gold Standards Framework, (National Gold Standards Framework Centre 2011) the Supportive and Palliative Care Indicators Tool (SPICIT™) (Boyd and Murray 2014) or the interRAI Palliative Care assessment (interRAI 2014) can assist to identify those people who need a transition of care. This may include a transition in the place of care, levels of care and/or goals of care.

End of Life Care covers the full range of clinical services provided. It incorporates treatments, programmes, policies, initiatives, benefits and entitlements that are provided for the person and their family/whānau/carers from the point when a life-threatening condition or illness is diagnosed until after the death, to include the care of the deceased person’s body and care of their family/whānau/carers.

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

Under new legislation (2007), a medical certificate that the person 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’ (Ministry of Health 2011).

F

Family: those closest to the person in knowledge, care and affection.

The family may include the biological family, the family of acquisition (related by marriage/contract), and the family of choice and friends (including pets) (Palliative Care Australia 2008).

See also Whānau.

⁵ Based on the work of Hui et al 2014. Amended for New Zealand and with the Inclusion of Last Days of Life in consultation with a working group of the Palliative Care Council.

G

Generalist Palliative Care: rather use 'Primary Palliative Care'.⁶

See the diagram of the relationship between Primary Palliative Care and Specialist Palliative Care in the definition of Primary Palliative Care.

H

Haumiri: to stroke or caress gently

Ko te āta miri, te āta morimori i te tinana.
The tender massaging or caressing of the body.

Hei Tauira Kōrero (example):

- Kia mutu te horoi i tō tātau Māmā, kia āta pēpēhi, kia āta haumiri haere i tōna tinana.
When we have finished washing Mum, gently press and massage her body.

Hinengaro: mind, thought, intellect, consciousness, awareness (Moorfield 2014).

Hine (female) is the conscious part of the mind and ngaro (hidden) is the subconscious. Hinengaro refers to the mental intuitive, feelings and emotions (Pere 1991).

Hiopeope: the intimate tending and nursing.

Ko te horoi, te huri me te tiaki i ngā āhuatanga katoa o te kiri whakahemohemo.
To gently wash, turn and look after all the needs of the dying person.

Hei Tauira Kōrero (example):

- Kia ngāwari te hiopeope nā te mea kei te mamae katoa a Pāpā.
Tend and nurse with care because Pāpā is feeling pain all over.

Holistic care: is comprehensive, total care that considers the physical, emotional, social, economic, and spiritual needs of the person; their response to the health condition; and the effect of the condition on their ability to meet self-care needs.

The principles of palliative care are framed around holistic care and the interdependent physical, social, emotional, cultural and spiritual aspects (Palliative Care Australia 2008).

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

The goal of hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high quality palliative care.

⁶ The term 'Generalist Palliative Care' is used in some countries but is not considered to adequately describe the nature of palliative care provided by health services that are other than specialist palliative care services. In New Zealand we use the term "Primary Palliative 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 (Hospice New Zealand 2015).

I–J

Interdisciplinary Team: a group of individuals with diverse training and backgrounds who work together as an identified unit or system.

Team members collaborate to solve problems too complex to be solved by one discipline alone, or several disciplines in sequence (Drinka and Clark 2000).

Membership varies depending on the services required to identify and address the expectations and needs of the person, caregiver and family. A palliative care interdisciplinary team typically includes one or more doctors, nurses, social workers, spiritual advisers, pharmacists, and personal care workers. Other disciplines will be part of the team as resources permit (Palliative Care Australia 2008).

interRAI: an acronym for International Resident Assessment Instrument. The name refers both to a suite of assessment instruments and to the organisation that developed them.

The interRAI organisation is a not-for-profit international collaborative network of researchers and clinicians (interRAI 2015).

The interRAI suite of assessment instruments is also known in New Zealand as the Comprehensive Clinical Assessment for Aged Care. The IT Health Board of the Ministry of Health is responsible for the implementation of this suite of assessment tools (NHITB 2015).

The interRAI Palliative Care Assessment System was developed to provide an assessment of the strengths, preferences, and needs of adults requiring palliative care and is intended to be used in both facility-based and community-based programs (interRAI 2014). A version of the interRAI Palliative Care assessment tool is being piloted for New Zealand.

K–L

Kaupapa Māori: Māori approach, Māori topic, Māori customary practice, Māori institution, Māori agenda, Māori principles, Māori ideology – a philosophical doctrine, incorporating the knowledge, skills, attitudes and values of Māori society (Moorfield 2015).

Kiri whakaahuru: carer, caregiver

Ko te hunga whakatau, te hunga āta poipoi i te kiri whakahemohemo i ōna rā whakamutunga. The people who settle and nurse the dying person in their last days.

Hei Tauira Kōrero (example):

- Me mihi tonu ki te kiri whakaahuru mō ō rātau pūkenga poipoi.
We should acknowledge the caregivers for their expertise in nurturing.

Takenga Mai (derivation): kiri – person, self; whakaahuru – to care with aroha.

Kiri whakahemoheho: dying person

Ko te tangata e tata nei tōna wā ki te whakawhiti i te ārai.
The person whose time of passing beyond the veil is drawing near.

Hei Tauria Kōrero (examples):

- Ko te kī a te rata kia āta hīopeope i te kiri whakahemoheho, he wā poto noa ki a ia.
The doctor advised to gently tend and nurse the dying person as there was only a short time left.
- Koia kei a ia ki te hiki i te wairua o te kiri whakahemoheho.
S/he was very good at lifting the spirits of the dying person.

Takenga Mai (derivation): kiri – person, self; whakahemoheho – on the point of death.

Last Days of Life: is the period when a person is dying. It is the period of time when death is imminent and may be measured in hours or days (Palliative Care Council 2015).

See also End of Life and the accompanying diagram.

Life-Limiting Condition: a condition for which there is no reasonable hope of cure and from which the person is expected to die.

Some of these conditions cause progressive deterioration rendering the person increasingly dependent on family and carers.^{7 8}

See also Life-threatening Condition and Terminal Condition.

Life-Threatening Condition: a condition for which curative treatment may be feasible but can fail.⁷

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

See also Life-limiting Condition and Terminal Condition.

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

Long-term conditions are sometimes known as 'chronic conditions', 'chronic diseases' or 'chronic illnesses' (Ministry of Health 2009).

See also Chronic Condition.

⁷ The original organisation cited in the New Zealand Palliative Care Glossary 2012 was the Association for Children's Palliative Care. The reference now redirects to Together for Short Lives: www.togetherforshortlives.org.uk/

⁸ The term 'illness' is not used as it implies a more narrow scope of health issues that impact on a person's quality of life.

M–N

Mana: authority, power, dignity

He kaha nō roto tonu i te tangata, nō te wairua, nō te hinengaro o te tangata.*

A strength emanating from within a person, from their spiritual, mental and emotional being.

Hei Tauira Kōrero (examples):

- Ka riro i a ia te mana hei māngai mō tōna koroua e whakahemohemo nei.
S/he was given the authority as spokesperson for her/his grandfather who was in his last days.
- Ko te mahi a ngā mātanga mohimohi, he āta tiaki i te mana o te kiri whakahemohemo.
The specialist caregivers work in a way to uphold the mana and dignity of the dying person.

Manaaki: to support, take care of, protect, show respect, hospitality

Ka āwhina, ka tiaki i runga i te ngākau pai, i te aroha rānei.

To help and provide care with a nurturing and loving spirit.

Hei Tauira Kōrero (example):

- E mōhio ana te whānau he tangata manaaki tō rātau pāpā, waihoki koia rā te tauira hei whai mā rātau.
The whānau acknowledged that their father is a warm-hearted and caring man, and that was the example they were following.

Māngai: spokesperson, representative

Ko te waha kōrero nā te whānau anō i tohu hei whakawhitiwhiti me ngā mātanga.

The person appointed by the whānau, or representing the whānau in deliberations with the specialists.

Hei Tauira Kōrero (example):

- Ko te tungāne me te tuahine pakeke ake ngā māngai kōrero i waenga i te whānau me ngā mātanga.
The older brother and sister were the spokespeople between the whānau and the specialists.

Mātanga: specialist

Ko ngā nēhi whai mātauranga me ngā rata e tiaki ana i te kiri whakahemohemo.

The qualified nurses and doctors who care for the dying person.

Hei Tauira Kōrero (example):

- Kāre he mutunga mai o te mihi a te whānau ki ngā mātanga hīopeope i tō rātau whanaunga.
The whānau had nothing but admiration for the specialist care provided for their loved one.

* He Pātaka Kupu.

Mātanga mohimohi: specialist caregivers

Ko te hunga whai mātauranga ka āta tiaki i te kiri whakahemohemo.
The group of qualified people who provide care for the dying person.

Hei Tauira Kōrero (example):

- Ka haere te mātanga mohimohi ki te whare o te whānau ki te tuku rongoā ki tō rātau māmā kia ngāwari ai ōna rā whakamutunga.
The specialist caregiver visited the whānau home to treat their mother to ease her last days.

Takenga Mai (derivation): mātanga – specialist; mohimohi – to tend, nurse – take care of.

Mate: death, die, pass away

Kua riro te mauri ora, kua kore i ora.*
The life force has been extinguished, life has ceased.

Hei Tauira Kōrero (examples):

- Nōnahea ia i mate ai.
When did s/he pass away?
- I reira te whānau katoa i tōna matenga.
The whole family was with her/him when s/he passed away.

Mate tara ā-whare, mate koeo: natural death

Ko te āta tuku i a Mate kia tau ana nā runga i te taikaumātua, waihoki kua mutu te whāngaihia ki te rongoa.
Dying naturally because of age, and the cessation of medication.

Hei Tauira Kōrero (example):

- Ka whakaae te whānau me ngā mātanga me tuku te kiri whakahemohemo kia **mate tara ā-whare**.
The whānau and specialists were in agreement that the person should be allowed to die naturally.

Mauri: life force, vital essence

Te mana atua kei roto i te tangata ki te tiaki i a ia, he tapu.*
The spiritual power within a person that provides protection, and is special or sacred.

Hei Tauira Kōrero (example):

- E tino kitea ana te heke haere o tana mauri i ōna rā whakamutunga.
Her/His weakening life force was clearly apparent in her/his last days.

* He Pātaka Kupu

Mauri rere: unsettled spiritual essence

E ohorere ana te mauri, e wehi ana, kāre e mōhio me aha.

The vital essence of a person is startled and in fear, not knowing what to do.

Hei Tauira Kōrero (example):

- Kua kore he kaipupuri i te hau o te kāinga me te aha, mauri rere ana te whānau.
There was now no-one to hold the essence of home, resulting in the whānau becoming unsettled.

Mauri tau: settled life force, serene

E tau ana te mauri, kāore e wehi ana.*

The vital essence of a person is settled, with no alarm or fear.

Hei Tauira Kōrero (examples):

- Āio ana tōna kanohi, he tohu tērā o tana mauri tau.
Her/His face was peaceful, showing that her/his vital essence was in a serene state.
- Nā te āio o te kanohi o tō rātau koroua, mauri tau ana te noho a te whānau i tōna taha.
Because the face of their grandfather was peaceful, the family was settled in their vigil at his side.

Minita: minister

Ko te kaituku i ngā inoi, i ngā karakia hei whakatau ā-wairua i te kiri whakahemohemo me tōna whānau.

The person who leads prayer, or does karakia to settle the spirit of the dying person and their whānau.

Hei Tauira Kōrero (example):

- Ia pō ka tau te minita o te hāhi Ringatū ki te tuku i ngā karakia i ōna rā whakamutunga.
In his/her last days, the Ringatū minister came every night to do karakia.

Mohimohi whakahemohemo: end of life care, palliative care

Ko ngā mahi whānui hei tiaki, hei tauawhi i te tangata i tōna wā whakahemohemo, tae atu hoki ki tōna whānau.

The broad range of practice to provide care and support to a dying person and their whānau.

Hei Tauira Kōrero (example):

- Mā te mahi tahi a ngā mātanga me te whānau e whakatauria ai ngā whakaritenga mō te mohimohi whakahemohemo.
The specialists working together with the whānau are able to decide on the provision for end of life care.

Takenga Mai (derivation): mohimohi – to tend, nurse, take care of; whakahemohemo – close to death.

* He Pātaka Kupu

Multidisciplinary team: a team that consists of a mix of health care disciplines.

Team members share common goals, collaborate and work together in planning and delivery of care. Members of a multidisciplinary team might include GPs, surgeons, medical or radiation oncologists, palliative care specialists, pastoral care workers, nurses, social workers, occupational therapists, physiotherapists, dieticians, volunteers, pharmacists or care assistants (Palliative Care Australia 2008).

Noa: free from the restrictions of tapu, ordinary

Ka noho wātea i ngā here o te taha wairua, ka noho tapu kore.*

Being free from spiritual restriction, having no sacredness or specialness.

Hei Tauira Kōrero (example):

- Mā te wai e whakanoa te hunga e puta atu ana i te rūma o te kiri whakahemohemo.
Water is used to cleanse people leaving the dying person's room, from the restrictions of tapu.

O–P

Palliation: is alleviation of symptoms when the underlying medical condition or pathological process cannot be cured.

The term is used widely in health care to refer to treatments or interventions (including surgical) that are focused on alleviation of pain or other symptoms, and is not necessarily limited to care provided for life-limiting and life-threatening conditions (Palliative Care Australia 2008).

The goal of palliation is to help a person feel more comfortable, and to improve quality of life. Palliation is a key goal of care for both end of life and palliative care.

Palliative Care:⁹ is care for people of all ages with a life-limiting or life-threatening condition which aims to:

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

Palliative care is provided according to an individual's need, and may be suitable whether death is days, weeks, months or occasionally even years away. It may be suitable sometimes when treatments are being given aimed at improving quantity of life.

It should be available wherever the person may be located.

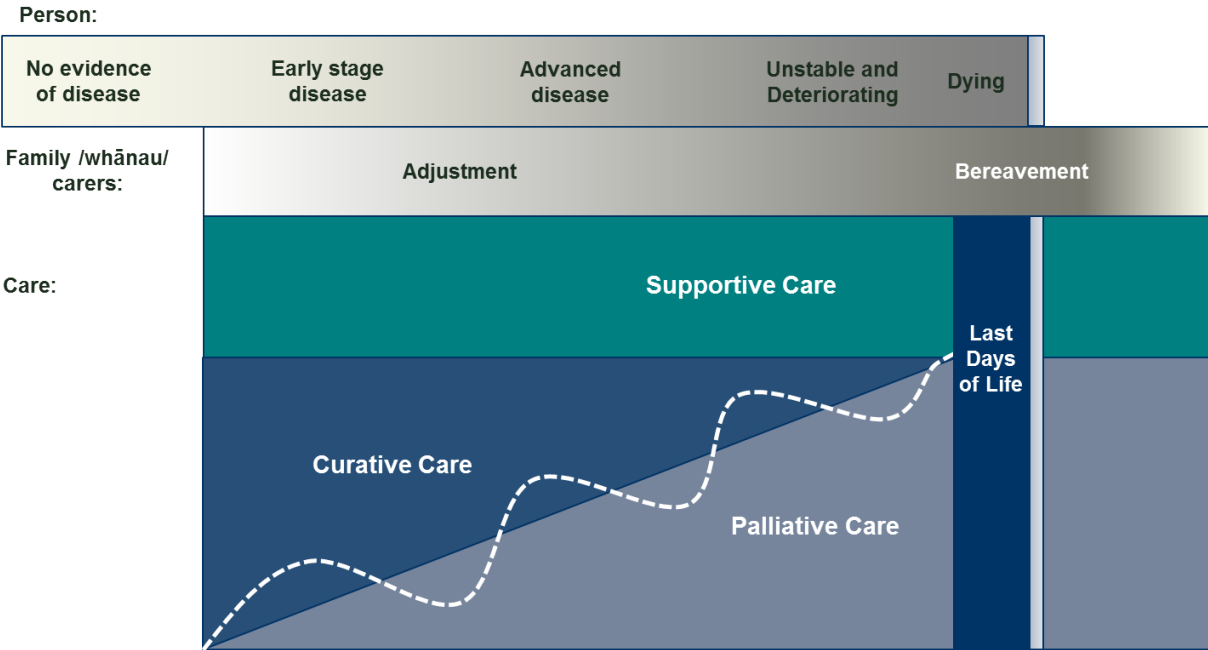
It should be provided by all health care professionals, supported where necessary, by specialist palliative care services.

* He Pātaka Kupu

⁹ This is the New Zealand specific definition of palliative care. See also Appendix A for the World Health Organization definition and subsequent clarification from the World Palliative Care Association.

Palliative care should be provided in such a way as to meet the unique needs of individuals from particular communities or groups. This includes but is not limited to; Māori, children and young people, immigrants, those with intellectual disability, refugees, prisoners, the homeless and those in isolated communities (Palliative Care Subcommittee NZ Cancer Treatment Working Party 2007).

Figure 2: Adjustment, support and palliative care for adults



Palliative Care Approach: an approach to care which embraces the definition of palliative care.

It incorporates a positive and open attitude toward death and dying by all service providers working with the person and their family, and respects the wishes of the person in relation to their treatment and care.

Palliative Care – Paediatric or Paediatric Palliative Care (PPC): Palliative care for children¹⁰ is the active total care of the child’s body, mind and spirit, and 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, psychological, 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 children’s homes, in community health centres and in tertiary care facilities.

Palliative care for children and young people is an active and total approach to care, from diagnosis or recognition throughout the child’s life, to death and beyond; embracing physical,

¹⁰ This is based on the World Health Organization definition, as given in full in Appendix A. A change in emphasis in the settings has been given by editing the original WHO text to reverse tertiary centres and home-based care. Note that the WHO is expected to revise the definition of paediatric palliative care during 2015.

emotional, social and spiritual elements. Focus is the enhancement of quality of life for the child or young person and support for the family.

Paediatric palliative care ¹¹ (Bergstraesser 2013) encompasses the management of distressing symptoms, through to care at the end of life and bereavement support. Palliative care may be introduced at any point in a child's life; it is completely individual. Some children may require palliative care from birth, others only as their condition deteriorates. Families may also vary as to whether they wish to pursue treatments to significantly prolong life.

Palliative care should be offered from diagnosis of a life-limiting condition or from determination that curative treatment for a life-threatening condition is not an option; however, each child is different and care should be tailored to the individual.

There are considered to be four groups of children to whom palliative care is needed¹² (Kidshealth 2015; Mellor et al 2012; Hain et al 2013; ACT/RCPCH 2009).

- Children with life-threatening conditions for which curative treatment may be possible but may fail. Palliative care may be necessary during periods when prognosis is uncertain and when treatment fails. Children who have had successful curative treatment or who are in long-term remission are not included.
- Children with conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities but where death could still occur.
- Children with progressive conditions, without the possibility of a cure. Palliative care of these children may be for many years.
- Children with conditions not usually considered progressive, but which may cause weakness and make children more vulnerable to complications. These children may deteriorate unpredictably.

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

Patient or Person: the primary recipient of care.

In the practice of palliative care, the person together with their family / whānau and carers are the focus of care.¹² The preferred term in New Zealand is person rather than patient.

Primary Carer (as distinct from Primary Care health professional): is generally in the close kin network of the person and is usually self-identified. The primary carer can be the person's spouse, child, another relative, family member or friend, or someone important to them.

The primary carer may be supported by other carers, but the primary carer generally will take the key role in the co-ordination and delivery of care and support to the person. This person

¹¹ This further explanation is edited from the paper on paediatric palliative care terminology by Bergstraesser.

¹² This wording is taken from the New Zealand Kidshealth website. The same categories are also expressed in the papers by Mellor and Hain and are based on the ACT/RCPCH definitions developed by the Royal College of Paediatrics and Child Health (RCPCH), working with the Association for Children's Palliative Care (ACT).

provides for the practical needs of the person and takes on additional tasks that may be of a technical nature, to provide ongoing care for the person, for example the administration of medications. They provide the primary support role for the person at all levels of need (Palliative Care Australia 2012).

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

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

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

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

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

See also Specialist Palliative Care and the accompanying diagram.

Puni haumarū: safe environment

He wāhi e noho ruru ai, e noho tau ai te kiri whakahemohemo.
A place where the person dying can be sheltered and settled.

Hei Tauira Kōrero (example):

- Ko te kāinga o tō rātau whaea tō rātau puni haumarū, nō reira mō ōna rā whakamutunga ka takoto ia ki reira.
Their mother's home was their safe environment, so that was where s/he lay in her/his last days.

Takenga Mai (derivation): puni – place of encampment, company of people; haumarū – to be safe.

Puni whakaahuru: hospice

He whare, he kāinga, he wāhi, he tāngata tauawhi i te kiri whakahemohemo e tiakina ai ia i ōna rā whakamutunga.

A building, a home, a place and a team of carers, where the dying person is looked after in their last days.

Hei Tauira Kōrero (example):

- Mōhio pai ana te whānau ko te Puni Whakaahuru te wāhi tika mō ngā rā whakamutunga o tō rātau koroua.

The whānau knew that the Hospice was the most suitable place for their grandfather in the last days of his life.

Takenga Mai (derivation): puni – place of encampment, company of people; whakaahuru – to care with aroha.

Q–S

Ringa opeope: person who tends and nurses

Ko tētahi o te whānau tata, ko te tino hoa rānei, ko tāna mahi he hīopeope i te kiri whakahemohemo, he mahi ngātahi hoki me te hunga mātanga.

A close family member, or close friend who undertakes the intimate care and nursing of the dying person, working together with the specialists.

Hei Tauira Kōrero (example):

- Ko tōna tino hoa tētahi o ngā ringa opeope i ōna rā whakamutunga.
His/Her best friend was one of those looking after their intimate care in their dying days.

Takenga Mai (derivation): ringa – hand; opeope (hīopeope) – intimate tending and nursing.

Rongōa: Māori traditional healing which is based on indigenous knowledge. It encompasses te ao Māori and a Māori view of being. Māori traditional healing practices include mirimiri (massage), rongoa (herbal remedies) and acknowledging te wairua (spiritual care). For Māori the unobservable (spiritual, mental and emotional) elements are as relevant as the observable or physical elements (Minister of Health 2002).

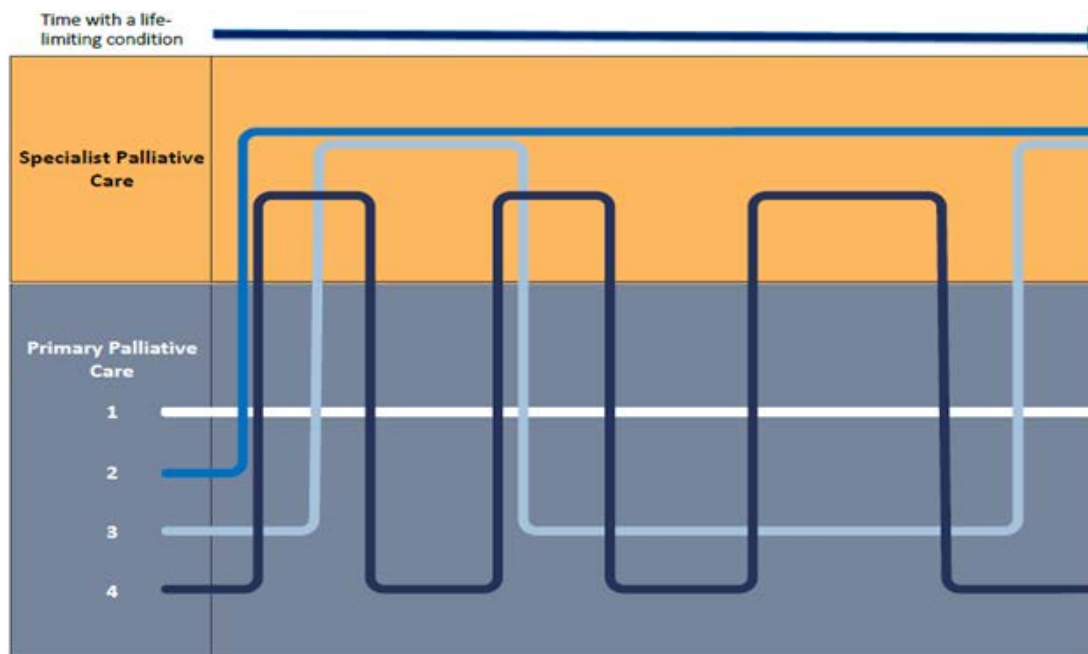
Specialist Palliative Care: is palliative care provided by those who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals.

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

Specialist palliative care is delivered in two key ways:

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

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



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

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

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

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

Supportive Care (in the context of cancer): care which aims to improve the quality of life for those with cancer, their family and whānau through support, rehabilitation and palliative care. Supportive care and rehabilitation services include the essential services required to meet a person's physical, social, cultural, emotional, nutritional, informational, psychological, spiritual and practical needs throughout their experience with cancer (Ministry of Health 2010).

T–V

Tapu: sacred, prohibited, set apart

Te mana atua me ōna here ka noho ki runga i ngā momo mea maha, tae noa ki te tangata.*
A spiritual power and its restrictions which apply to many different things including people.

Hei Tauira Kōrero (example):

- Kei te mōhio te tamāhine he tapu ki tōna whaea ōna kākahu roto, nō reira ko ia anahe te kaihoroi i aua kākahu.
The daughter knew that her mother considered her undergarments as tapu, so she was the only one to wash them.

Te Ara Whakapiri: the path of closeness and unity.

The Māori name for the principles and guidance for the last days of life, as developed by the Palliative Care Council. This guidance represents the recommended approach to caring for all people in New Zealand across all sectors and settings who have a life-limiting illness and are in their last days of life (Palliative Care Council 2015).

See also Last Days of Life.

Te Wā Aroha: a time of love or time of compassion.

The Māori name for the Starship Children's Hospital end of life care plan (Kidshealth 2014).

See: Advance Care Planning, Allow Natural Death and End of Life Care.

Te Whare Tapa Whā: a Māori model of health. This model compares health to the four walls or cornerstones of a house. All four cornerstones are required to maintain positive wellbeing. When one of the cornerstones becomes damaged or is missing, the person may become unbalanced or unwell.

- Te Taha Tinana – physical health
- Te Taha Hinengaro – psychological health
- Te Taha Wairua – spiritual health
- Te Taha Whanau – family health (Ministry of Health 2012).

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 (Palliative Care Australia 2008).¹³

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

W–Z

Whakaaro nui: accord respect, treat with dignity

Ko te aro kia tau te wairua, te tinana me te hinengaro o te kiri whakahemohemo.
A focus on settling the person's spirit, mind and body.

Hei Tauira Kōrero (example):

* He Pātaka Kupu

¹³ The term 'illness' is not used as it implies a more narrow scope of health issues that impact on a person's quality of life.

- **Ko te whakaaro nui** a te mokopuna ki tōna koroua, me heru tonu ōna makawe ahakoa kua kore ia e aro ake, ina he tangata huatau ia i tōna wā.
The grandchild was able to accord respect to his grandfather by continuing to comb his hair, even though he was not conscious of this, as his grandfather was one who took pride in his appearance.

Whakahemohemo: close to death, dying

Kua tata te wā ki te whakawhiti ki tua o te ārai. Kua tata te ringa kaha o Mate.

Drawing near to the time of crossing over to beyond the veil. The closing in of the strong hand of Death.

Hei Tauira Kōrero (examples):

- **Ahakoa e whakahemohemo ana ia, e mauri tau ana.**
His/her mauri was in a settled state even though s/he was on the point of dying.
- **Mīharo pai ana te whānau ki te mahi a ngā mātanga whakaahuru i te wā e whakahemohemo ana tō rātou kuia.**
The whānau was in total admiration of the care provided by the team of specialists at the time their grandmother was dying.

Whakapapa: genealogy, genealogical table, lineage, descent – reciting whakapapa was, and is, an important skill and reflected the importance of genealogies in Māori society in terms of leadership, land and fishing rights, kinship and status. It is central to all Māori institutions (Moorfield 2015).

Whānau: extended family, family group, a familiar term of address to a number of people. In the modern context the term is sometimes used to include friends who may not have any kinship ties to other members (Moorfield 2015).

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

Whānau ora is driven by a focus on whānau being self-managing, living healthy lifestyles and confidently participating in te ao Māori and in society. It is a key element of pae ora and is an important part of setting the foundations for healthy futures. Each whānau is different and has a unique set of aspirations. To achieve whānau ora, the health system will work in a way that acknowledges these aspirations and the central role that whānau play for many Māori, as a principal source of strength, support, security and identity (Minister of Health 2002).

Whānau whakaruru: whānau support

Ko te whānau tata, ngā whanaunga, ngā hoa pātata ki te kiri whakahemohemo.
The close family and relations, and close friends of the dying person.

Hei Tauira Kōrero (example):

- **Inā te mahi a te whānau whakaruru, he tautoko i ngā mātanga me te kiri whakaahuru i roto i ā rātau mahi katoa.**
The role of whānau support is to uplift and assist the specialists and carers in all they do.

Takenga Mai (derivation): whānau – family, extended family; whakaruru – shelter, protect.

Whare Tapa Whā: He anga hauora nā Ahorangi Mason Durie, i takea mai i te whakaaro Māori. Ka whakaritea te hauora o te tangata ki ngā tapa e whā o te whare. Mā ēnei tapa katoa e mārō ai te tū o te whare, e pai ai te hauora whānui o te tangata. Koia ko te taha ki te hauora o te tinana; ko te taha whānau, arā, te hauora ka hua ake i te noho a te tangata ki roto i te āhuru mōwai o tōna whānau, tōna hapori anō hoki; ko te taha hinengaro, arā, te puna whakaaro o te tangata ki a ia anō me te ao whānui; ko te taha wairua, arā, te mana atua o roto i te tangata me āna whakapono.

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

Hei Tauira Kōrero (example):

- Ko tā te Puni Whakaahuru e whai ana, kia hāngai tonu ā rātou mahi katoa ki te anga o Te Whare Tapa Whā.
The Hospice was aiming to ensure that all of their practices were in line with the Whare Tapa Whā framework.

Takenga Mai (derivation): whare – house, building; tapa – side, edge; whā – four.

Wherū: absolute weariness

Ko te pau o te hau, waihoki o te kaha o te tinana, e rangona ai te ngenge kino.
The depletion of vitality and bodily strength to a point of experiencing extreme weariness.

Hei Tauira Kōrero (example):

- Ka tau te tino wherū ki tō rātau matua ka whakaae te whānau kia tukuna ia ki tāna haere roa.
Their father came to a point of such absolute weariness that the whānau agreed that he should be released to his long journey.

References

- ACT/RCPCH. 2009. *A Guide to the Development of Children's Palliative Care Services*. Bristol, UK: Together for Short Lives.
- Association for Children's Palliative Care. *Information: Children's palliative care definitions*. Bristol: Association for Children's Palliative Care. URL: www.togetherforshortlives.org.uk/
- Barlow C. 1991. *Tikanga Whakaaro: Key Concepts in Māori Culture*. Victoria, Australia: Oxford University Press. URL: <http://ukcatalogue.oup.com/product/9780195582123.do>
- Bergstraesser E. 2013. Pediatric palliative care: a reflection on terminology. *Palliat Care* 7: 31–6. URL: www.ncbi.nlm.nih.gov/pubmed/25278760
- Boyd K, Murray S. 2014. *Supportive and Palliative Care Indicators Tool (SPICT™)*. NHS Lothian and The University of Edinburgh Primary Palliative Care Research Group. URL: www.spict.org.uk
- Drinka TJK, Clark PG. 2000. *Health care teamwork: Interdisciplinary practice and teaching*. Westport, CT: Auburn House.
- Hain R, Devins M, Hastings R, et al. 2013. Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. *BMC Palliat Care* 12: 43. URL: www.ncbi.nlm.nih.gov/pubmed/24330676
- Hazinski MF, Samson R, Schexnayder S. 2010. *Handbook of Emergency Cardiovascular Care for Healthcare Providers*. URL: www.nlm.nih.gov/medlineplus/ency/article/000010.htm
- Hospice New Zealand. 2015. What is Hospice? Wellington: Hospice New Zealand. URL: www.hospice.org.nz/hospice-care/what-is-hospice
- Hui D, Nooruddin Z, Didwaniya N, et al. 2014. Concepts and definitions for 'actively dying,' 'end of life,' 'terminally ill,' 'terminal care,' and 'transition of care': a systematic review. *J Pain Symptom Manage*. 47: 77–89. URL: www.ncbi.nlm.nih.gov/pubmed/23796586
- interRAI. 2014. *interRAI Palliative Care (PC)*. URL: www.interrai.org/palliative-care.html
- interRAI. 2015. *interRAI Coordinating Centre: Australia and New Zealand*. URL: www.interrai-au.org/index.htm
- Kidshealth. 2014. *Allow Natural Death / Te wa aroha*. Paediatric Society of New Zealand and Starship Foundation. URL: www.kidshealth.org.nz/allow-natural-death-te-wa-aroha
- Kidshealth. 2015. *Palliative care for children: Introduction*. Paediatric Society of New Zealand and Starship Foundation; 2014. URL: www.kidshealth.org.nz/allow-natural-death-te-wa-aroha
- Mellor C, Heckford E, Frost J. 2012. Developments in paediatric palliative care. *Paediatrics and Child Health* 22: 115–20. URL: www.sciencedirect.com/science/article/pii/S175172221100268X

- Minister of Health. 2002. *He Korowai Oranga – Māori Health Strategy*. Wellington: Ministry of Health Manatū Hauora 47. URL: www.health.govt.nz/our-work/populations/maori-health/strategic-direction-maori-health
- Ministry of Health. 2009. *Report on New Zealand Cost-of-Illness Studies on Long-Term Conditions*. Wellington: Ministry of Health. URL: www.health.govt.nz/publication/report-new-zealand-cost-illness-studies-long-term-conditions
- Ministry of Health. 2010. *Guidance for Improving Supportive Care for Adults with Cancer in New Zealand*. Wellington: Ministry of Health. URL: www.health.govt.nz/publication/guidance-improving-supportive-care-adults-cancer-new-zealand
- Ministry of Health. 2011. *Advance Care Planning: A guide for the New Zealand health care workforce*. Wellington: Ministry of Health. URL: www.health.govt.nz/publication/advance-care-planning-guide-new-zealand-health-care-workforce
- Ministry of Health. 2012. *Māori health models – Te Whare Tapa Whā*. URL: www.health.govt.nz/our-work/populations/maori-health/maori-health-models/maori-health-models-te-whare-tapa-wha
- Moorfield JC. 2014. *Te Aka Online Māori-English, English-Māori Dictionary and Index 2014*. URL: www.maoridictionary.co.nz/
- Moorfield JC. 2015. *Te Aka Online Māori-English, English-Māori Dictionary and Index 2015*. URL: www.maoridictionary.co.nz/
- National Ethics Committee. 2012. *Māori Research Ethics: An overview*. Wellington: National Ethics Committee – Kāhui Matatika o te Motu, Ministry of Health.
- National Gold Standards Framework Centre. 2011. *The GSF Prognostic Indicator Guidance* (4th edition, October). The Gold Standards Framework Centre in End of Life Care. URL: www.goldstandardsframework.org.uk/LibraryofResourcesPresentationsandLinks.html
- National Health IT Board. 2015. *Comprehensive Clinical Assessment for Aged Care (interRAI)*. URL: <http://ithealthboard.health.nz/our-programmes/common-clinical-information/comprehensive-clinical-assessment-aged-care-interrai>
- Palliative Care Australia. 2005. *A Guide to Palliative Care Service Development: A population based approach*. Deakin West, ACT: Palliative Care Australia. URL: www.pallcare.org.au
- Palliative Care Australia. 2008. *Palliative and End of Life Care. Glossary of Terms* (Edition 1). Deakin West, ACT: Palliative Care Australia, 24. URL: www.palliativecare.org.au/portals/46/pca%20glossary.pdf
- Palliative Care Council. 2012. *New Zealand Palliative Care Glossary*. Wellington: Palliative Care Council of New Zealand, Hospice New Zealand and the Ministry of Health. URL: <http://cancercontrolnz.govt.nz/pub/new-zealand-palliative-care-glossary>
- Palliative Care Council. 2015. *Principles and Guidance for the Last Days of Life: Te Ara Whakapiri – The Path of Closeness and Unity*. Wellington: Palliative Care Council of New Zealand.

Palliative Care Subcommittee NZ Cancer Treatment Working Party. 2007. *New Zealand Palliative Care: A Working Definition 5*. URL: www.health.govt.nz/publication/new-zealand-palliative-care-strategy

Pere RRT. 1991. *Te Wheke: A celebration of infinite wisdom*. URL: <http://www.unibooks.co.nz/new-zealand/Maori/te-wheke-a-celebration-of-infinite-wisdom>

US National Library of Medicine. 2015. *Bereavement*. Bethesda, MD: National Institutes of Health. URL: <http://vsearch.nlm.nih.gov/vivisimo/cgi-bin/query-meta?query=bereavement&v%3Aproject.nlm-main-website>

Worldwide Palliative Care Alliance, World Health Organization. 2014. *Global Atlas of Palliative Care at the End of Life*. London & Geneva 111. URL: www.thewpca.org/resources/global-atlas-of-palliative-care/

Appendix A: WHO Definition of Palliative Care

World Health Organization (WHO) Definition, 2002¹⁴

For adults

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

Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten or postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patient's live as actively as possible until death
- offers a support system to help the family cope during the patients 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.

For children

Palliative care for children represents 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 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 giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

¹⁴ The World Health Organization (WHO) definition of palliative care was published in 2002 and remains unchanged. In 2014, the Global Atlas of Palliative Care added further explanatory text (Worldwide Palliative Care Alliance, World Health Organization. 2014). For completeness, the 2002 definition and the extension in 2014 are shown.

- Health providers must evaluate and alleviate a child's physical, psychological, 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.

Further explanation in 2014

It has been recognised for some years that the definition above, which has been in use since 2002, requires further explanation to ensure the definition is more explicit and transparent (Worldwide Palliative Care Alliance, World Health Organization. 2014).

First, palliative care is needed in chronic as well as life-threatening/ limiting-conditions.

- Adults with a wide range of chronic conditions throughout the world have been recognised as benefiting from palliative care. Early intervention, well before the terminal stage, is recognised as optimal.
- The WHO definition of palliative care for children states that palliative care should be provided to children with chronic and life-limiting illness, not only those who are dying. Paediatric palliative care begins when the illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.

Second, there is no time or prognostic limit on the delivery of palliative care.

- It has been widely advocated that palliative care should be delivered on the basis of need, not diagnosis or prognosis.
- Although we have estimated numbers based on mortality data for consistency, palliative care should be provided 'early in the course of the illness' (WHO definition of palliative care) and at least as many people are estimated to have palliative care needs before the last year of life as during the last year of life.

Third, there is a need for palliative care at all levels of care.

- Palliative care is not limited to specialist palliative care services but includes primary and secondary level care.
- Palliative care is provided at three different levels:
 - i) through a 'palliative care approach' adopted by all healthcare professionals, provided they are educated and skilled through appropriate training;
 - ii) 'general palliative care' provided by primary care professionals and those treating patients with life-threatening diseases, with a good basic knowledge of palliative care, and
 - iii) 'specialist palliative care' provided by specialised teams for patients with complex problems.

- The requirement for provision at the three different levels will vary from country to country, depending on the proportion of deaths from palliative care diagnoses, according to models of healthcare, and the nature and extent of integration of palliative care within these models.

Fourth, **palliative care is not limited to any one care setting.**

- Palliative care is provided wherever a person's care takes place, whether this is the patient's own home, a care facility, hospice inpatient unit, hospital, or outpatient or day care service.

The relationship between curative and palliative care

The relationship between curative and palliative care plays out differently in different countries and societies, for a variety of reasons. However, we emphasise that palliative care should in no way become a substitute for appropriate curative care.

- Modern medical care has a strong bias towards curative medicine. In high income countries, death is frequently medicalised, and curative treatments may be prioritised ahead of palliative care. Better, and earlier, integration of palliative care alongside active treatment is needed.
- For low and middle income countries, however, curative care and active management may be very limited, or not available at all. Palliative care is needed, but not as a substitute for development of healthcare systems and provision of appropriate services.
- In some societies, the cultural context may mean that death and dying are often stigmatised, such that perceptions and taboos need to be challenged before palliative care provision can be addressed.

The Worldwide Palliative Care Alliance recommends that all governments integrate palliative care into their country's health system, alongside curative care. At a minimum, palliative care should be provided even when curative care is unavailable.