The Palliative Care Glossary was prepared by:

Wayne Naylor
Senior Analyst
Palliative Care Council of New Zealand

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Contact information:
Palliative Care Council of New Zealand
PO Box 5013
Wellington 6145
New Zealand

AMI Plaza, Level 5, Lambton Quay
Wellington

Phone +64 4 815 9800
Email office@palliativecarecouncil.govt.nz

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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 Wayne Naylor, Senior Analyst, Palliative Care Council of New Zealand on (04) 815 9800.
**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\(^1\) (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’.\(^2\)

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)\(^2\).

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\(^2\).

**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/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\(^2\).

**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.\(^3\)
**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.

**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).

**Dying:** A person is considered to be dying when they are in the process of passing from life to death. 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/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/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.

**End of Life Care Plan:** An end of life care plan can be used instead of a Do Not Attempt Cardiopulmonary 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 Wa 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’.
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).

See also Whānau.

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.]

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.

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.¹¹

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.⁵

**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.⁸

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.⁸ 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/whânau in the last days and hours of life, irrespective of diagnosis or care setting.¹²

**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.¹³

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.5

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”.14 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.5

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.15

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.16 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, whanau, 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 Maori, 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.\(^5\)

**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.\(^5\)

**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, Maori 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.*

**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.\(^17\)

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).13

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.15

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.18

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

T, U, V

Te Wa Aroha: Te Wa Aroha is the title in Te Reo Maori given to the Starship Children's Hospital end of life care plan. Te Wa 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.5

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."^{19}
References


5 Palliative Care Australia. (2008). *Palliative and end of life care glossary of terms* (1st Edn). Deakin West, ACT: Palliative Care Australia.


