



**PALLIATIVE AND END OF LIFE CARE
GLOSSARY OF TERMS**

Edition 1 2008



**Palliative
Care
Australia**

Palliative Care - Glossary of Terms –Edition 1 2008

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Palliative Care Australia

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FOREWORD

The Council and Executive of Palliative Care Australia (PCA) is pleased to present the first edition of the *Palliative Care and End of Life Care Glossary* (the Glossary). This document has been developed in consultation with the members of PCA and other key stakeholders.

As the first edition, this Glossary represents the beginning of an ongoing process to seek clarity and consistency in the way that we describe end of life care. Much has changed in the experience of dying and in the delivery of care over the past three decades in Australia. In some cases our ability to articulate these changes has not kept pace with the reality.

Importantly, we have shifted from a concern primarily about the needs and requirements at the end of life for people with cancer to a broader concern with the needs of all Australians at the end of life. However, we continue to use terminology and language that came into use almost three decades ago in very different clinical environments, to communicate about end of life care needs and service responses in more contemporary health care environments.

This first edition of the Glossary attempts to set out some of the intended and unintended meanings of terminology in common usage and to provide recommendations for the use of specific terms. We believe that a collaborative process to seek consistency will enhance our ability to communicate clearly and unambiguously the needs of patients and families at the end of life and to describe the health and social care systems' response to those needs.

We look forward to your contribution to the ongoing development of this Glossary and to a spirited and rigorous process of discussion and debate to build agreement on a common language to take us into the future.

Your comments and contributions can be sent to pcainc@palliativecare.org.au or provided to Sue Hanson, National Quality & Standards Director, Palliative Care Australia by telephone (02) 6232 4433.



Professor Margaret O'Connor AM

President
Palliative Care Australia
June 2008

MESSAGE FROM PCA NATIONAL QUALITY & STANDARDS DIRECTOR

There have been many changes in the experience of dying and in the delivery of care to people at the end of life in Australia over the past three decades. More people are dying of chronic and complex conditions, with longer periods between diagnosis and death¹. Patients and families with these conditions have become better informed about the availability of services to provide care and support during this period and are seeking access to services.

Palliative care services, predominately established to provide care to cancer patients who were dying, now find that they need to respond to the needs of patients with different diagnoses². Service delivery models have needed to be developed or modified to accommodate this increasing demand for care and new ways of describing the patients, their needs and the care provided have been introduced. This new language has included terms such as 'end of life', 'palliative approach' and 'primary palliative care provider'.

The introduction of some of these terms has had some unintended consequences. There are now a variety of ways that the same type and level of care or need can be described. There is a lack of clarity about the relationship between need and service type or response.

Palliative Care Australia has developed this Glossary to encourage the consistent use of terminology and improve clarity in communication about palliative and end of life care. We believe that the consistent use of language will, over time, reduce confusion and ensure clear and unambiguous communication between levels of service providers and between services, patients and the wider community.

Our language must work to support the full implementation of needs-based end of life and palliative care in accordance with PCA's national service provision policies and standards, and Commonwealth and jurisdictional service delivery frameworks.

¹ J Lynn, 2008. 'Palliative care beyond cancer: Reliable comfort and meaningfulness', www.bmj.com [Accessed 16/04/2008]

² S.Murray et al. 2004. 'Developing primary palliative care: People with terminal conditions should be able to die at home with dignity.' *BMJ* 329; 1056 – 1057.

THE IMPORTANCE OF LANGUAGE

As new understandings of the needs of people at the end of life emerge it is becoming apparent that we need to communicate clearly and unambiguously with groups of people with different perspectives and needs. The language that we use and the meanings that are attached to specific terms becomes increasingly problematic as we seek to negotiate new roles and responsibilities to ensure quality care for all Australians at the end of life.

The lack of consistency in our use of terminology has created and will continue to create confusion as we seek to communicate and understand the needs of different cohorts of people facing the challenges of, providing or needing end of life care, including palliative care. The need to differentiate between the different resource and skill levels in services produced new terms, as did the need to respond to the challenges of increasing demand. For example, how might we explain the difference between palliative care and a palliative approach to a patient, their carer or family? What is the difference (if any) between the terms 'life limiting', 'life threatening' or 'terminal illness'? Do the words carry different meaning for different cultures and different people? How are these words interpreted by patients, carers and health professionals? Which of them signify most closely the meaning we wish to communicate? What unintended meanings have become attached to particular words or terms? Lacking a precise or agreed definition these terms have come to be used to represent vastly different (qualitatively and quantitatively) things to different people.

It is our hope that this Glossary will stimulate reflection, discussion and debate about the current use of some of these terms and that this in turn will lead to improved communication about end of life and palliative care.



Sue Hanson
National Quality & Standards Director
Palliative Care Australia
June 2008

USING THE GLOSSARY

The first edition of the Glossary is intended to take the first steps towards the development of an agreed, commonly understood and utilised language to describe end of life and palliative care and the people who need it.

It is important to use different language in communication with different people and in different situations and it is up to the individual to determine the most appropriate choice of terms and language for any given circumstances. The Glossary is an important tool that can assist individuals to choose words and terms that convey a precise and clear message.

The Glossary identifies some terms that are NOT recommended as they are unclear or have the potential to cause misunderstanding or confusion. Where a term is NOT recommended an alternative, preferable term is given.

Terms that are recommended are marked with an asterisk (*). These are terms that have the clearest meaning most closely associated with current philosophy or policy.

In introducing the Glossary, PCA highlights the importance of ongoing review and revision to ensure that it can achieve its goal of improving the clarity and consistency of communication.

Your feedback and contribution is essential to this ongoing improvement process. Please send any comments or suggestions for improvement to pcainc@palliativecare.org.au or contact Sue Hanson, National Quality & Standards Director, Palliative Care Australia on (02) 6232 4433.

End of Life Care Providers

Needs-based care in accordance with PCA service delivery model



A

Advance care directives*

A set of documents containing instructions that consent to, or refuse, specified medical treatments and that articulate care and lifestyle preferences in anticipating future events or scenarios. They become effective in situations where the person is no longer able to make decisions. For this reason advance care directives are also, though less frequently, referred to as living wills¹.

An advance care directive has legal status and therefore is part of the separate legislative arrangements in each State and Territory in Australia.

Advance care planning*

The process of preparing for likely scenarios near the end of life that usually includes assessment of, and discussion about, a person's understanding of their medical condition and prognosis, values, preferences and personal and family resources². Respecting Patient Choices³ is one of many programs that supports advance care planning.

Advance care planning supports patients in communicating their wishes about their end of life.

B

Bereavement

Bereavement is the total response to a loss and includes the process of 'recovery' or healing from the loss. Although there are similarities in people's responses, there are also marked differences. Each person will grieve and 'recover' in their own way⁴.

C

Chronic and complex 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 ongoing³. Chronic and complex conditions are characterised by persistent and recurring health consequences lasting for an extended period of time.

Note that this Glossary proposed 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

Dying*

A person is considered to be dying when they are in the process of passing from life or ceasing to be.

E

End of life*

That part of life where a person is living with, and impaired by, an eventually fatal condition, even if the prognosis is ambiguous or unknown.

End of life care*

End of life care combines the broad set of health and community services that care for the population at the end of their life.

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

Eventually fatal 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 illness and ageing.

A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise.

The terms *eventually fatal* or *terminal condition* are used interchangeably. In reference to the patient: language that refers to 'living with an eventually fatal (or terminal) condition' is recommended.

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)⁶.

H

Holistic

Holistic is a whole made up of interdependent parts. You are most likely to hear these parts referred to as the mind/body connection: mind/body/spirit, or physical/mental/emotional/spiritual aspects. When this meaning is applied to the treatment of illness, it is called holistic medicine and includes a number of factors, such as dealing with the root cause of an illness, increasing patient involvement and considering both conventional and complementary therapies.

The principles of palliative care are framed around holistic care and the interdependent physical, social, emotional, cultural and spiritual aspects.

Hospice

A hospice is a comprehensive service provided to people living with and dying from an eventually fatal condition. This may include inpatient medical care, respite care and end of life care for people who are unable to die at home. Hospices may also offer day care facilities and community home visiting teams.

I

Interdisciplinary team*

An interdisciplinary team is a team of providers who work together to develop and implement a plan of care. Membership varies depending on the services required to identify and address the expectations and needs of the patient, caregiver and family. An interdisciplinary team typically includes one or more doctors, nurses, social workers, spiritual advisers, pharmacists, and personal care workers. Other disciplines may be part of the team if resources permit⁷.

L

Life-limiting illness or condition

(Not recommended. Terminal condition or eventually fatal condition preferred)

M

Multidisciplinary team

A multidisciplinary team 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.

N

Needs-based end of life care*

Needs-based end of life care is a quality management approach that evaluates the individual holistic needs of the patients and their families and carers and coordinates appropriate care.

The end of life needs of many patients are appropriately met by primary care (generalist, and other specialist and support care) providers with specialist palliative care providers contributing direct, indirect care or consultation advice as required.

This approach recognises that patients with more complex needs may require periodic or ongoing direct care from specialist palliative care providers.

P

Paediatric palliative care

The WHO definition of palliative care for children defines paediatric palliative care as a special, albeit closely related field to adult palliative care. The principles of the WHO definition of care appropriate for children and their families 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 homes⁸.

Palliation

To palliate is to alleviate a symptom without curing the underlying medical condition. 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 eventually fatal conditions.

Palliation in relation to end of life care is the relief of symptoms and suffering caused by cancer and other all eventually fatal conditions. Palliation helps a patient feel more comfortable and 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 care*

Short definition

Palliative care is specialist care provided for all people living with, and dying from an eventually fatal condition and for whom the primary goal is quality of life.

Full definition in accordance with the World Health Organisation

Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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 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 complications⁹.

Palliative approach

A palliative approach is a term that has been used to describe care that aims to improve the quality of life for individuals with an eventually fatal condition, and their families, by reducing their suffering through early identification, assessment and treatment of pain, physical, psychological, social, cultural and spiritual needs¹⁰.

Patient

A patient¹¹ 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.

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, eg the administration of medications. They provide the primary support role for the patient at all levels of need¹².

Primary generalist providers*

In the context of end of life care, a primary care provider is the first contact medical, nursing or allied health professional, who undertakes an ongoing role in the care of patients with an eventually fatal condition. In general the substantive work of a primary generalist provider is not in the care of people who are dying.

Primary care providers in end of life care include:

- General practitioners
- Community nurses
- Allied health professionals
- Pharmacists
- Staff of residential aged care facilities/aged care homes
- Health professionals in acute care hospitals
- Trained volunteers.

Primary care services provide on-going support from diagnosis through to the death of the patient, in accordance with PCA's population based service provision models¹³.

Primary care services assess and refer patients to specialist palliative care providers 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 generalist, primary specialist and support care providers and the community – working together to meet the needs of all people.

Primary specialist providers*

In the context of end of life care, other primary specialist providers include all other specialists that have first contact and include oncologists, renal, cardiac or respiratory physicians. In general, their substantive work is not in palliative care.

Q

Quality standards

The 13 standards for providing quality palliative care for all Australians¹⁴ provide a framework of minimal standards for systems of care at the end of life.

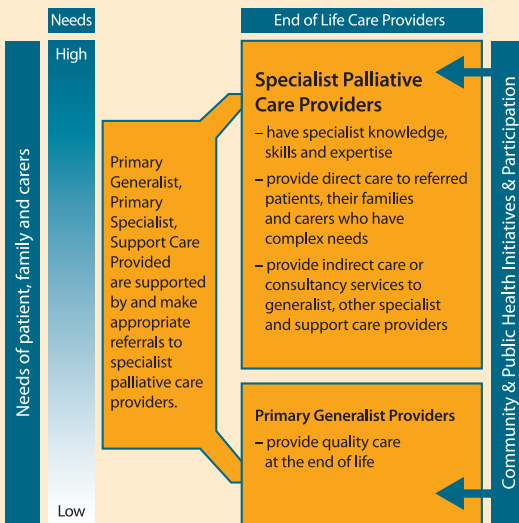
S

Specialist palliative care provider*

A specialist palliative care provider is a medical, nursing or allied health professional recognised as a palliative care specialist by an accrediting body or who substantively works in a specialist palliative care service if an accrediting body is not available.

A palliative care specialist has the specialist knowledge, skills and expertise in care of people living with an eventually fatal condition and their families and carers, including in the management of complex symptoms, loss, grief and bereavement.

The Australian & New Zealand Society of Palliative Medicine (ANZSPM) recognises two training pathways to achieve palliative medicine specialist status and has established criteria for recognition as either a Consultant Physician in Palliative Medicine or Palliative Medicine Specialist¹⁷.



Specialist palliative care services*

Specialist palliative care services are provided by an interdisciplinary team of specialist palliative care professionals whose substantive work is with patients who have an eventually fatal condition. Specialist palliative care services are provided in care settings including community, home, hospitals, aged care homes and hospices and palliative care units.

Specialist palliative care services work in three key ways in accordance with PCA's service provision model¹⁸.

- Providing direct care to referred patients with complex needs
- Providing consultation based services to patients being cared for by primary care providers
- Providing support and education to services providing end of life care.

Support care/support care providers*

Support care providers include assistants in nursing and personal care staff in aged care homes, volunteers, charitable organisations, complimentary therapists (for example, massage therapists, music therapists and aromatherapists), pastoral carers, and others who provide a supporting role in the care of a patient living with an eventually fatal condition and their family and carers.

T

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 illness and ageing.

A person has an eventually fatal condition if their death in the foreseeable future would not be a surprise.

The terms *eventually fatal* or *terminal condition* are used interchangeably. In reference to the patient: language that refers to 'living with an eventually fatal (or terminal) condition' is recommended.

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- ¹ Adapted from NSW Health (2005). Using Advance Care Directives (NSW). NSW Health
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- ⁸ Adapted from the Centre to Advance Palliative Care. Available at www.capc.org
- ⁹ WHO Definition of Palliative Care for Children (1998). Accessed at <http://www.who.int/cancer/palliative/definition/en/>. Accessed 28/04/08
- ¹⁰ World Health Organisation
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- ¹³ Palliative Care Australia (2005). A Guide to Palliative Care Service Development: A population based approach
- ¹⁴ Standards for Providing Quality Palliative Care for all Australians. 4th Edition 2005, Palliative Care Australia
- ¹⁵ Department of Primary Industry and Energy (1994). Rural, Remote and Metropolitan Area Classifications (RRMA). Canberra: Commonwealth of Australia
- ¹⁶ Ibid
- ¹⁷ For more detailed information see www.anzspm.org.au
- ¹⁸ A Guide to Palliative Care Service Development: A population based approach. 2nd Edition 2003 Palliative Care Australia

POPULATION AND NEEDS-BASED PLANNING FOR CARE AT THE END OF LIFE

The goal of care at the end of life is to maximise quality of life through appropriate needs-based care for each person at the end of life.

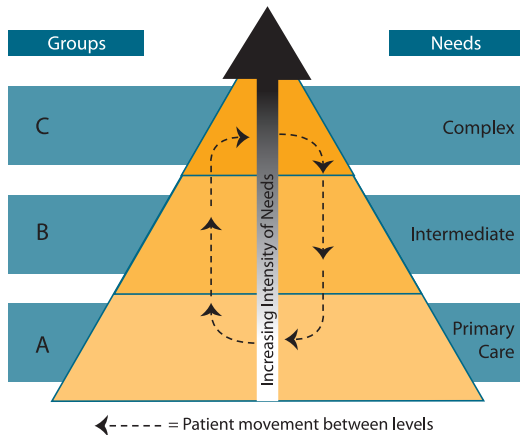
End of life is that part of life where a person is living with, and impaired by, an eventually fatal (or terminal) condition. End of life is not always a finite point, however the principles of care apply even if the prognosis is ambiguous or unknown.

All health professionals and the community have a responsibility to care, when required, for people at the end of life and thus require a level of knowledge and skill in the philosophy and practice of palliative care. For quality care to be realised for all, recognition of the body of evidence and expertise in palliative care is essential for enabling appropriate referral and access.

Quality care at the end of life is provided by health professionals along a continuum of care – from primary or generalist care providers to specialist palliative care providers, based on the individual's needs and choices.

The Council of Palliative Care Australia endorsed a national policy document in February 2005, *A Guide to Palliative Care Service Development: A population based approach*. This document suggests a plan for providing equitable access to care in the context of efficient, effective and ethical use of resources. The following diagram, from this document, illustrates the conceptual model for consumer focused care, based on defining this population and their needs.

The end of life population is not a homogenous population group – it is time to define the population more precisely.



For the purposes of population based service planning, it is proposed that all people at the end of life (including their family, caregiver/s and community) be conceptualised as falling within three broad sub-groups. Based on the best available estimates of expected deaths in Australia per annum, the population represented in the conceptual model is 100,000.

The largest **sub-group A** are those patients who do not require access to specialist care as their needs are met either through their own resources or with the support of primary care providers (for example generalist medical and nursing services as well as other specialist staff – oncologists, cardiac services, geriatricians and so on). Currently, almost two-thirds of all people whose death is expected fall within sub-group A and are not seen by a specialist palliative care service prior to their death.

Fewer than a third of patients represented in the model are currently seen by palliative care services. These patients are distributed between sub-groups B (those patients requiring consultation care) and C (those requiring ongoing specialist care). It is not known how they are proportionally distributed between sub-groups B and C.

In **sub-group B**, patients may have sporadic exacerbations of pain or other physical symptoms or may experience social or emotional distress. This temporary increase in their level of need may require access to specialist palliative care services for consultation and advice. They will continue to receive care from their primary care provider.

Sub-group C are those palliative care patients who have been identified as having complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care. They usually require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care providers. This sub-group is likely to be the smallest of the three sub-groups of the population.

Palliative Care Australia believes:

- every Australian at the end of life should have timely and equitable access to quality, needs-based and evidence-based care, where:
 - timely is determined by the needs of the patient and their family and caregivers
 - equitable access is ensured regardless of age, ethnicity, location, diagnosis or disease prognosis.
- patient, family and caregiver needs (physical, social, emotional, spiritual and cultural), balanced with an assessment of individual and collective resources and limitations, should be the criteria used to determine appropriate levels of care for people.

PCA's membership comprises the eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine.

Together, the PCA members network to foster, influence and promote local and national endeavours to realise a vision of quality care at the end of life for all.

There are many opportunities to participate in the palliative care community:

- Become a member of your local palliative care organisation (see contact details opposite)
- Register to receive regular news and information updates by email through PCA Connect (accessible via www.palliativecare.org.au).

To find out more about palliative care services across Australia, visit the National Palliative Care Service Directory (accessible via www.palliativecare.org.au).

PCA Member Organisations

NSW	Palliative Care NSW PO Box M48 Missenden Road NSW 2050	Phone: +61 403 699 491 Email: info@palliativecarensw.org.au Website: www.palliativecarensw.org.au
QLD	Palliative Care Queensland 117 Copperfield Street Geebung QLD 4034	Phone: +61 7 3633 0096 Fax: +61 7 3633 0086 Email: help@pallcareqld.com Website: www.pallcareqld.com
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WA	Palliative Care WA 46 Ventnor Avenue West Perth WA 6005	Phone: +61 8 9212 4330 Fax: +61 8 9212 4330 Email: pcwainc@palliativecarewa.asn.au Website: www.palliativecarewa.asn.au
SA	Palliative Care Council of South Australia 202 Greenhill Road Eastwood SA 5063	Phone: +61 8 8291 4137 Fax: +61 8 8291 4122 Email: pallcare@pallcare.asn.au Website: www.pallcare.asn.au
TAS	Tasmanian Association for Hospice and Palliative Care c/- Association Offices GPO Box 448 Hobart TAS 7001	Phone: +61 3 6234 7577 Fax: +61 3 6234 7566 Email: natasha@associationoffices.com.au samantha.stennings@associationoffices.com.au
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