

STRATEGIC PLAN 2008-2011

Palliative
Care
Australia

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1 – OUR ORGANISATION

Palliative Care Australia is the peak national organisation representing the interests and aspirations of all who share the ideal of quality care at the end of life for all.

Specialist palliative care providers have specialist knowledge, skills and expertise in the care of patients, their families, carers and communities, who are living with and dying from a terminal condition.

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.

2 – OUR VISION

Quality care at the end of life for all.

3 – OUR MISSION

To influence, foster and promote the delivery of quality care at the end of life for all

Palliative Care Australia works to see equitable, needs-based delivery of quality care at the end of life through:

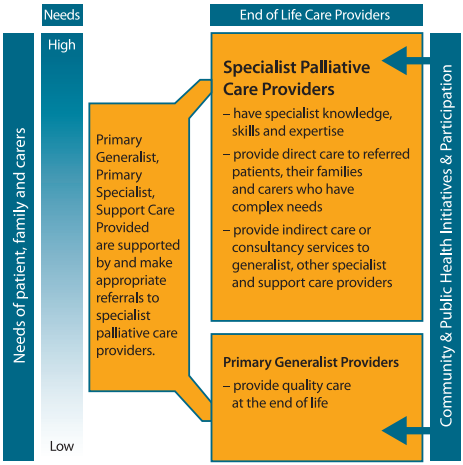
- promotion of the principles of palliative care
- development of needs-based service provision models
- workforce capacity building
- awareness and community capacity building
- appropriate funding and resourcing.

Palliative care must be:

- quality – in accordance with the Palliative Care Australia *Standards for Providing Quality Palliative Care for All Australians*
- timely
- resourced to enable choice
- needs-based – in accordance with individual level of need
- evidence-based – in accordance with most current research.

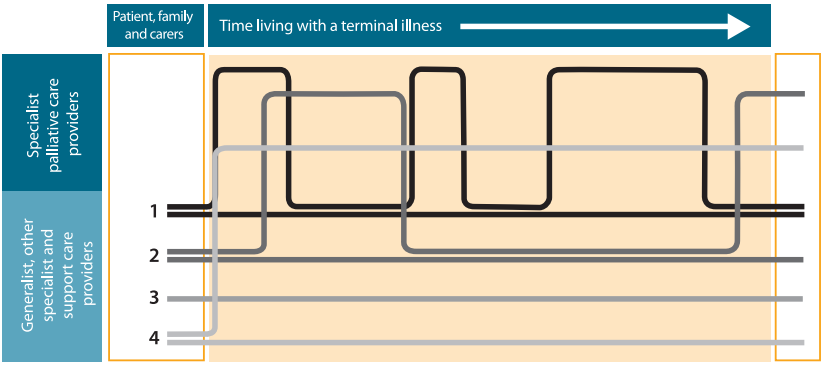
Palliative care must be available regardless of:

- location
- age
- income
- diagnosis or prognosis
- social and cultural background.



The Palliative Care Australia Framework for provider networks to deliver quality care at the end of life.

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.



The responsive models of interaction between primary generalist, other specialist palliative care providers, illustrate the involvement of, and linkages between, all providers of care to meet the changing needs of patients, their families and carers.

4A – OUR STANDARDS

Palliative Care Australia leads the development of national standards that form the key governing document influencing both primary specialist services and providers in the way they deliver care at the end of life.

Standards for Providing Quality Palliative Care for all Australians (The Standards) provide a framework of minimal standards for systems of care at the end of life.

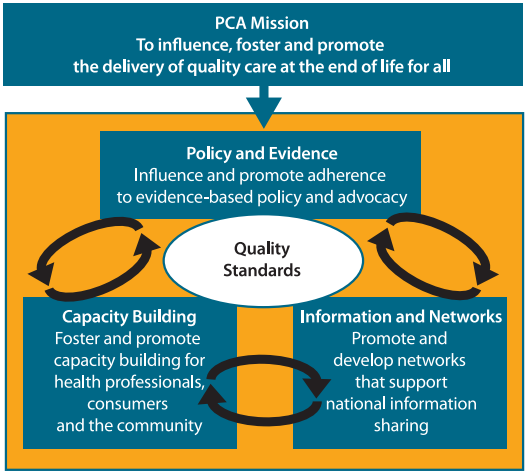
The Standards underpin all strategic, policy and program activities undertaken by Palliative Care Australia.

The Standards represent a commitment to the stated ideals of quality care at the end of life for all Australians.

4B – OUR PRINCIPLES

All endeavours of Palliative Care Australia are guided by the following principles of operation:

- **partnerships and collaboration** – recognising that working with others holding similar goals will assist the delivery of better outcomes
- **contribution of members** – recognising, valuing and utilising the contribution, expertise and experience of the Palliative Care Australia members
- **quality and integrity of outcomes** – being strategic, evidence-based, professional, transparent and showing leadership on palliative care issues
- **quality of work environment** – upholding the right of staff and volunteers to work in a focussed and productive team in a safe and supportive environment
- **recognising cultural diversity** – respecting and being sensitive to people from diverse cultural and linguistic backgrounds and their community ties.



5 – STRATEGIC AIMS – PROGRAM OUTCOMES

Palliative Care Australia works to achieve the following program outcomes:

1 – Fully integrated national health and social policies are informed by innovative, evidence-based principles for *quality care at the end of life*.

Influence and promote the development and adherence to evidence-based policy, through work to:

1.1 – review, develop and deliver national quality standards, policy documents and submissions reflecting current evidence base

1.2 – establish coordinated networks that work to integrate national quality standards and policy across the health sector

1.3 – establish economic rationale for investment in quality care at the end of life.

2 – Health professionals, patients, families, consumers and the community commit to the principles for *quality care at the end of life* and have access to the systems, skills and resources to match their role.

Foster and promote capacity building for health professionals, consumers and the community through work to:

2.1 – strengthen consumer (patient, family, carer and community) awareness and capacity

2.2 – strengthen specialist palliative care workforce recognition, resourcing and capability in care delivery

2.3 – strengthen the capacity of the primary generalist, primary specialist and support provider workforce to deliver care.

3 – Networks of organisations, health professionals and consumers enable access to and share information to improve the realisation of *quality care at the end of life for all*.

Promote and develop networks that support national information sharing through work to:

3.1 – establish collaborative alliances with other individuals and organisations

3.2 – enable efficient and timely access to quality endorsed national information resources

3.3 – enable efficient and effective conduct of working groups, special interest groups and committees.

6 – STRATEGIC AIMS – CORPORATE OUTCOMES

Palliative Care Australia works to achieve the following corporate outcomes:

4 – Strategically independent with robust governance

4.1 – maintain national leadership and the pre-eminent source of quality information on end of life

4.2 – maintain effective governance of Executive, Council, subcommittees and working groups

4.3 – ensure the Palliative Care Australia Principles and Standards guide all activity.

5 – Effective and valued partnerships

5.1 – work with, value and support the PCA members and promote the expansion of their membership

5.2 – link and collaborate with national health and community organisations

5.3 – support the PCA members to link and collaborate with state health and community organisations.

6 – Well resourced and managed organisation

6.1 – maintain sound financial and management systems

6.2 – attract and retain skilled and experienced staff

6.3 – achieve financial sustainability and independence.

7 – Achievement of targets, goals and contract deliverables

7.1 – effectively plan for program delivery

7.2 – effectively manage program risks

7.3 – align program activities across corporate strategy, policies and systems including the PCA members.

7 – GOVERNANCE AND MEMBERS

Palliative Care Australia's membership comprises the eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. These organisations created and share the vision, mission and aims of Palliative Care Australia and operate through a federated governance structure.

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

Individuals and organisations, who share this vision, are able to participate in the work of Palliative Care Australia in the following ways.

State based or local individuals, service providers and organisations

In addition to the benefits conferred through membership of a Palliative Care Australia member organisation, individuals or organisations have automatic access to:

- Palliative Care Australia's communication resources
- reduced registration fees to the National Conference.

National organisations

Membership of the Quality Care at the End of Life Alliance allows for:

- access to information and networks to support policy and practice development towards quality care at the end of life, within their respective constituencies.

8 – ACKNOWLEDGEMENTS

Palliative Care Australia acknowledges its work is enabled through the extraordinary professional and personal commitment of the Palliative Care Australia volunteer officer bearers, Palliative Care Australia members and staff. Together we strive to realise our vision.

Palliative Care Australia acknowledges the financial support of the Australian Government Department of Health and Ageing.

End of Life Care Providers

Needs-based care in accordance with PCA service delivery model



Palliative Care Australia

GLOSSARY

Palliative care is a growing health care area, as evidenced by the increasing involvement of health professionals, communities and individuals.

As new understandings of the needs of people at their end of life, and new models of care have emerged over the past two decades, so too has a range of terminology and language been developed and used to describe patients, carers, providers and services.

Palliative Care Australia has developed this Glossary to support the consistent use of terminology to improve clarity in communication about palliative care. We believe that the consistent use of language will, over time, reduce confusion and ensure clear and unambiguous communication.

Our shared communication challenge is to use language that fully supports well informed and appropriate community demand for care – and does not imply a 'quality differential' across the range of providers and services involved.

Our language must work to realise the full implementation of needs-based end of life and palliative care in accordance with PCA's service provision policy.

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 or the least potential to cause misunderstanding or confusion.

In producing this Glossary, Palliative Care Australia highlights the importance of consulting, reviewing and regularly revising the Glossary.

Your feedback and contribution is essential to this ongoing improvement cycle. Please send any comments or suggestions to pcainc@palliativecare.org.au or Donna Daniell, CEO, Palliative Care Australia.

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 wills[1].

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 resources[2]. Respecting Patient Choices[3] 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 way[4].

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 ongoing[5]. 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 permit[7].

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 homes[8].

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 complications[9].

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 needs[10].

Patient

A patient[11] 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 need[12].

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 models[13].

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 proving quality palliative care for all Australians[14] 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 Specialist[17].

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 model[18].

- 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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