Supporting Australians to Live Well at the End of Life

National Palliative Care Strategy 2010

Endorsed by Australian Health Ministers.

National Palliative Care Strategy 2010

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Introduction

The pattern of life, disease, dying and death has changed dramatically in Australia both over the last century and over the last several decades. In 1907 in Australia, 45,305 people died while the mean age of death was 41[1]. In 2008, there were 143,932 deaths in Australia and the median age at death was 80.9[2].

Over the past 20 years, life expectancy at birth has improved by 6.1 years for males and 4.2 years for females. Based on current mortality rates, a boy born in 2006–2008 can expect to live 79.2 years while a girl can expect to live 83.7 years. According to United Nations estimates for 2005–10, Australia's life expectancy at birth is ranked among the highest in the world[3].

Increased life expectancy has brought with it much higher rates of chronic disease. Many people carry non life-threatening chronic conditions such as arthritis, hearing and vision loss, and mental illness with them into their final years. These conditions don't threaten life expectancy, but can significantly affect a person's well being and health care needs.

More serious life limiting chronic conditions such as dementia, cardiovascular and respiratory diseases, and cancers are also increasing and have changed the pattern of death.

Most healthy Australians, when asked where they would prefer to die, nominate their home as their preference. However, the statistics on place of death indicate that this is relatively uncommon — only 16% of people die at home. Twenty per cent of people die in hospices and 10% in nursing homes. The rest die in hospitals[4]. This results in a high cost burden for the health system[5, 6] and potentially a poorer quality of death[7].

Of the 144,000 people who die annually in Australia, the proportion whose death is anticipated is variously reported between 25 and 50%[8]. That suggests there are between 36,000 and 72,000 people with potential palliative care needs. However, not all people approaching the end of life need specialist palliative care. The provision of appropriate, high quality care for people at end of life occurs every day across Australia through a palliative approach from general practitioners, community nurses, care workers, family and others. However, there are unmet needs of many from defined population groups and those with specific conditions.

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1 Australian Institute of Health and Welfare (AIHW) 2008. GRIM (General Record of Incidence of Mortality) Books. Canberra.
2 Australian Bureau of Statistics (ABS) 2009, 3302.0 Deaths, Australia, 2008, Canberra.
3 Australian Bureau of Statistics (ABS) 2009, 3302.0 Deaths, Australia, 2008, Canberra.
4 CareSearch Preferred Place of Death accessed 14 April 2010 www.caresearch.com.au
5 Kardamanidis K, Da Cunha C, Taylor L, Jorm L. Hospital costs of older people in New South Wales in the last year of life. MJA 2007; 187 (7): 383-386
6 Lynn J, Adamson D. 2003 Living well at the end of life. RAND Health White paper.
7 Finlay I, Higginson I, Goodwin D, Ann Oncol. Palliative care in hospital, hospice, at home: results from a systematic review.2002;13 Suppl 4:257-64. PCA DYING WELL Palliative Care Australia submission outlining ideas and priorities for the 2010-11 Federal Budget
8 Palliative Care Australia. 2005 A Guide to Palliative Care Service Development: A population based approach.

Introduction, Continued

This may include Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds. It may also include people living in rural and remote locations, people who are socially or financially disadvantaged, veterans and their spouses, people living on their own, people in the justice system, children and adolescents, people with mental health issues, people with disabilities and people with life limiting non-malignant conditions including dementia, motor neurone disease and HIV/AIDS. There exists the opportunity to improve approaches to ensure all Australians receive quality needs based care at the end of their life.

Palliative Care Services in Australia

Over the last 20 years in Australia the specialisation of palliative care has advanced considerably. Palliative care is provided in almost all settings where health care is provided including neonatal units, paediatric services, acute hospitals, general practices, residential and community aged care services, and generalist community services.

Specialist palliative care services operate from a variety of settings including specialist inpatient consulting services, specialist inpatient settings, hospices and community based specialist services.

Specialist palliative care services have a vital role in providing expert clinical advice – particularly for those with complex symptoms requiring palliation, as well as the provision of direct care for a small number of patients and more broadly the provision of capacity building and support services to the broader health and human services sectors.

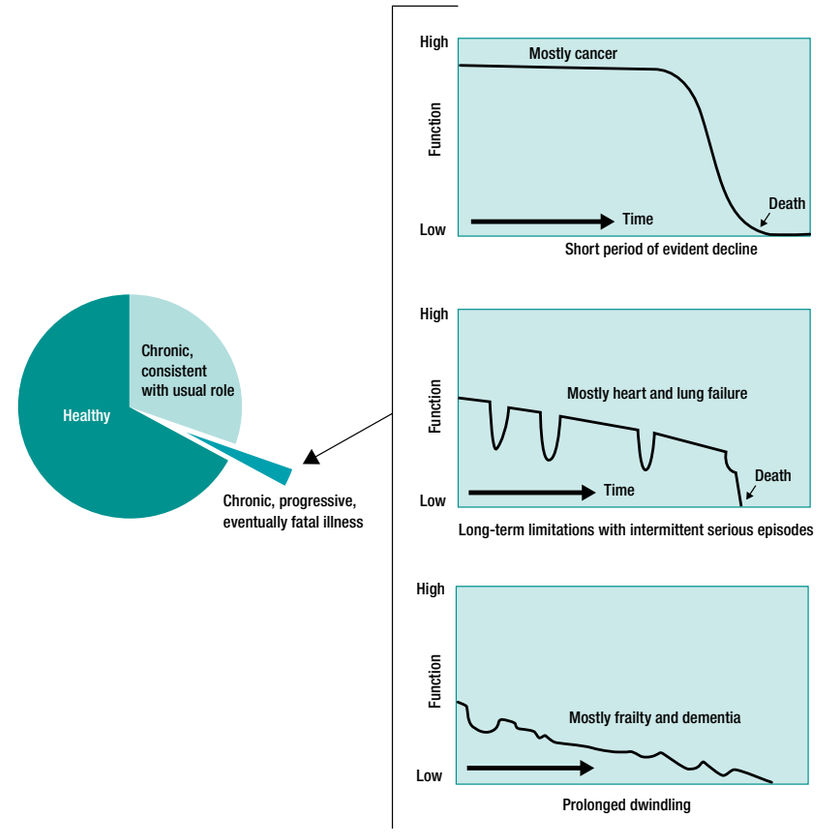
Palliative care is also an intrinsic part of all health and human services in their overall responsibilities in providing comprehensive care to their clients. Integration and collaboration with specialist palliative care services can then ensure capacity building and enhanced quality of care.

It will be important in the life of this Strategy to ensure that both specialist and generalist / primary health aspects of palliative care continue to be strengthened.

With the increasing number of clients with a range of complex disease patterns and an increase in the number of cancer clients, new approaches to care and service models are required. The trajectory of various disease types is depicted in Diagram 1. Unlike cancer clients who experience considerable decline in a shorter period of time prior to death and where the need for palliative care services may be more obvious, clients with chronic conditions have a much longer disease trajectory with difficult prognostication. Additionally, a larger number of clients exist with more complex chronic conditions involving multiple co-morbidities. The need for palliative care may not be as obvious and may involve multiple, shorter encounters.

Introduction, Continued

Diagram 1: The disease trajectories of chronic illness[9]



9 Lynn J, Adamson D. 2003 Living well at the end of life. RAND Health White paper.

Introduction, Continued

Scope of Palliative Care

The scope of palliative care includes not only the specialist palliative care services, but also care offered through primary care providers in a variety of settings. Given the widening scope of palliative care, the term palliative care when used in this document is intended in its broadest sense to encapsulate both specialist and generalist care. The term end of life is used to indicate issues broader than care needs and services.

A number of definitions exist for palliative care, to which differing sectors of services adhere. The Commonwealth recognises that State and Territory jurisdictions and various parts of the sector work under different definitions. Each State and Territory jurisdiction has articulated their definition in their state / territory strategic documents.

Palliative care is defined by the World Health Organization[10] as:

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 or 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 patients illness and in their own bereavement;*
- *uses a team approach to address the needs of patients and their families, including bereavement counseling, 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.*

This is the definition adopted by the Palliative Care Intergovernmental Forum as the national definition of palliative care.

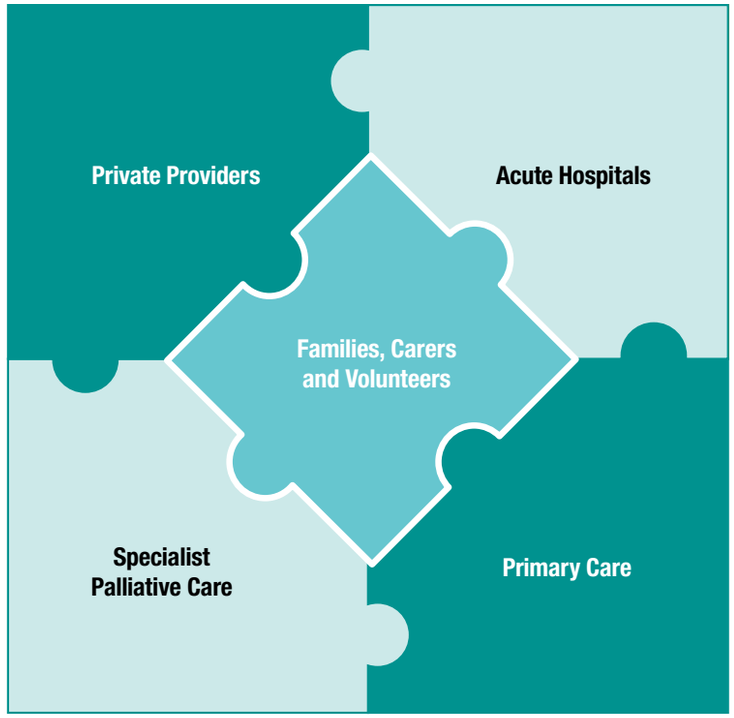
10 http://www.who.int/cancer/palliative/definition/en/

Introduction, Continued

Scope of Palliative Care (continued)

Within Australia palliative care is provided across the health and human services spectrum by: public hospitals, private hospitals, general practitioners, justice health services, disability services and specialist palliative care services – public and private, in both inpatient and community based settings as depicted in Diagram 2.

Diagram 2: The Palliative Care Service Picture



Whilst there is a National Palliative Care Program that supports national approaches, most palliative care service provision occurs within the remit of the State and Territory health systems. Each State and Territory has an articulated approach to palliative care in their jurisdiction. This Strategy aims then to enhance and build on the work occurring at the jurisdictional level, not duplicate or contradict it.

The Strategy

The National Palliative Care Strategy History

The development of the National Palliative Care Strategy (NPCS) commenced in 1998 and was endorsed in October 2000 by Australian Health Ministers' Advisory Council. The NPCS represents the combined commitments of the Commonwealth, State and Territory Governments, palliative care service providers and community-based organisations to the development and implementation of palliative care policies, strategies and services that are consistent across Australia.

The NPCS (2000) was a stand-alone document which set objectives and strategies intended to inform policy and service development across Australia, guide States and Territories in their planning for the development of palliative care services and in supporting patient care agencies.

It was also intended to provide the framework for the Commonwealth, States and Territories to work together cooperatively and collaboratively in ensuring that resource allocation occurred in concert with the development of palliative care services, and that palliative care policy, planning and service delivery would be directed towards common and agreed goals.[11]

The Impact of the Strategy

The National Palliative Care Strategy Activity Implementation Report (2005), subsequent literature scan and stakeholder consultation undertaken as part of the development of this updated National Palliative Care Strategy, clearly demonstrates there has been a wealth of important activity which has occurred at all levels around the development of palliative care services.

The NPCS 2000 has been key in advancing the sector's capacity through:

- increased understanding of palliative care in the health sector
- providing a focal point for State and Territory activities
- providing the overall direction for the National Palliative Care Program.

Ten years on, whilst much has happened and there are demonstrable achievements, gaps and deficiencies still remain in the provision of high quality palliative care service provision. In order to meet future demand and provide equitable access to all Australians, when and where they need it, further work is required.

11 National Palliative Care Strategy, 2000, Commonwealth Department of Health and Aged Care

The Strategy, Continued

The Updated National Palliative Care Strategy

Supporting Australians to Live Well at the End of Life (the National Palliative Care Strategy 2010) — has been developed following extensive consultation and research. Eight workshops were held across Australia in March 2010 and an extensive on line survey was undertaken by 320 people. This provided a significant amount of data on the views of stakeholders on the directions, priorities and potential strategies for inclusion in this update. The draft updated Strategy was then provided for further consultation with 127 stakeholders providing feedback to inform this final document.

The scope of the updated National Palliative Care Strategy 2010 is broad, addressing both palliative care provided in all specialist and general settings as well as end of life issues.

This update occurred at a time of major health care reform in Australia. Whilst these reforms continue to be developed to address the needs of a changing and ageing population, it is clear that the demand for high quality palliative care across Australia will inevitably increase. To meet this demand all parts of the health and human services sector will need to focus on the following four goal areas:

- Awareness and Understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability.

Each of these goal areas are further defined in this Strategy with goal statements, objectives and action areas. Some suggested measures of success are listed for each goal area. These measures will require refinement and translation into measurable performance indicators as part of the development of implementation and work plans to support the translation of the Strategy into practice. The measures are not intended to be comprehensive but rather indicative of overall improvements in the delivery of quality palliative care to all Australians who need it.

The consultation reports produced as part of the update of the Strategy contains useful suggestions regarding specific approaches to the action areas listed in the Strategy. It is recommended that these documents be reviewed in the planning of specific work areas.

The clear message of demand emerging from the stakeholder consultation process in the development of this Strategy is that Australians want a system that supports Australians to live well at the end of life. Implementation of this Strategy will ensure Australia continues to be a world leader in the provision of first class palliative care services.

Overview of Goal Areas

Goal Areas

Four goal areas have been identified for the National Palliative Care Strategy 2010, namely:

- Awareness and Understanding
- Appropriateness and Effectiveness
- Leadership and Governance
- Capacity and Capability.

This section provides a brief overview of the context for each goal areas and a table of the specific goals for each.

Awareness and Understanding

There is a need to significantly enhance the understanding of dying, death, grief, bereavement and loss in Australia, including in health professionals and carers, to support better access to appropriate, timely services across the end of life continuum.

Building awareness and understanding must be undertaken in a culturally respectful way. Death and dying is an extremely personal matter. For some cultures there are explicit norms around how these issues are approached. Given that one-quarter of Australians come from a culturally and linguistically diverse background, awareness campaigns and services themselves must be culturally safe and appropriate.

Appropriateness and Effectiveness

Appropriateness is about ensuring the right approach, in the most suitable setting in a timely manner. Appropriateness requires good systems and processes to support access to information and services. This is critical to the provision of high quality palliative care.

Effective care is also about providing those interventions which are supported by an evidence base and providing them effectively and efficiently.

Appropriate and effective care systems need to be supported by a strong research base and services that have good systems of quality control and cultures of quality improvement.

Overview of Goal Areas, Continued

Leadership and Governance

Governance is key to the improvement and implementation of strategy. This is particularly so given the diversity of the service system for palliative care. The investment of resources at the national, State and Territory and local levels will be enhanced through stronger, more visible and accountable leadership and governance of national palliative care approaches.

Capacity and Capability

High quality palliative care requires adequate capacity and capability. In essence that means sufficient numbers of appropriately skilled people in the right place with adequate systems to support safe, quality care.

There has been significant investment in palliative care resources – training, facilities, workforce numbers, equipment and clinical resources. Building capacity and capability is not simple and requires more than just investment. It is important to recognise that capacity building initiatives often have long lead times. Any investment will need to be targeted, particularly with regards to education and training to ensure sustainable outcomes.

Action should be explored as a priority to mitigate the combined effects of workforce shortages, ageing of the palliative care workforce and increasing demand on palliative care service provision in all parts of Australia.

Overview of Goal Areas, Continued

Goal Summary

The following table summarises the goals in each goal area. The following pages detail the action areas under each goal.

Table 1: National Palliative Care Strategy 2010 Goals

goal area	number	goal
Awareness and Understanding	Goal 1	To significantly improve the appreciation of dying and death as a normal part of the life continuum.
	Goal 2	To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.
Appropriateness and Effectiveness	Goal 3	Appropriate and effective palliative care is available to all Australians based on need.
Leadership and Governance	Goal 4	To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.
Capacity and Capability	Goal 5	To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

Awareness and Understanding

Goals

Goal 1:
To significantly improve the appreciation of dying and death as a normal part of the life continuum.

Goal 2:
To enhance community and professional awareness of the scope of, and benefits of timely and appropriate access to, palliative care services.

Action Areas

Action will be undertaken to:

1. Develop a comprehensive, evidence based, multi-modal and targeted national public awareness strategy to promote death as a normal part of living and promote the services and options available for people nearing the end of life.
2. Promote collaborative integration of health and human services and increase the visibility of end of life issues, palliative care and roles and responsibilities.
3. Provide mechanisms to ensure palliative care providers across the continuum are aware of, and provide, culturally appropriate palliative care and end of life support including care preferences, spiritual requirements and bereavement expression.
4. Support the national roll out of Advance Care Planning across all sectors (primary, acute, aged care) including addressing any barriers to uptake.
5. Encourage the integration of palliative care training within all health undergraduate and relevant post-graduate curricula.

Measures of Success

Measures of success for this goal will be to identify:

1. Improvements in public awareness.
2. Improvements in integration between service sectors.
3. Uptake of Advance Care Planning.
4. Improvements in palliative care training.

Appropriateness and Effectiveness

Goals

Goal 3:
Appropriate and effective palliative care is available to all Australians based on need.

Action Areas

Action will be undertaken to:

1. Continue to support a continuous quality improvement approach to meet national standards for palliative care service provision and work with national standards bodies to incorporate appropriate standards.
2. Support the evolution of innovative models of palliative care service provision.
3. Support the development of integrated/coordinated models of palliative care service provision.
4. Develop a national template with triggers for referral to specialist palliative care services that can be customised for their own setting.
5. Support the national roll out of an integrated care pathway across all sectors (primary, acute, aged care), including addressing any barriers to uptake.
6. Incorporate specific references to palliative care and the end of life phase in all relevant national and state plans, frameworks and clinical guideline documents.
7. Develop an appropriate mechanism to review national outcome data from relevant standards and accreditation processes to drive further improvements across specialist palliative care services.
8. Support a national bereavement care framework collaboration. Undertake longitudinal research into bereavement in palliative care.
9. Management of storage and release of the deceased body[12].

12 This is particularly required for certain cultural groups and settings. For example, there are significant issues in the Northern Territory wet season with the inability to undertake burials in some areas, and with the pressure on hospitals and aged care providers to free up beds.

Appropriateness and Effectiveness, Continued

Measures of Success

Measures of success will include:

1. Outcome data and trends from relevant data collections.
2. Standards are intrinsic in the various health care standards and accreditation mechanisms.
3. An Australia-wide roll out of:
   - end of life care pathway
   - palliative care referral pathway.
4. Evidence in best practice bereavement practices within a palliative care setting.

Leadership and Governance

Goals

Goal 4:
To support the collaborative, proactive, effective governance of national palliative care strategies, resources and approaches.

Action Areas

Action will be undertaken to:

1. Strengthen the role of the Palliative Care Intergovernmental Forum (PCIF) by establishing a work plan and formal reporting responsibilities to the Australian Health Ministers Advisory Council (AHMAC).
2. Ensure mechanisms for formal communication, engagement and linkages throughout the sector to address:
    - Research collaboration, funding, priorities and dissemination of outcomes
    - Clinical leadership
    - Consumer engagement
    - Leadership across all areas of health and human services for end of life issues
    - Coordination between national program providers
    - Priority setting and tracking of project funding with a focus on consolidating outcomes from previous projects
    - National measurement of both palliative care service provision and quality, and the implementation and outcomes of this Strategy
    - Workforce
    - Palliative care in the health context.

Measures of Success

Measures of success for this goal will include:

1. The inclusion of PCIF in formal reporting requirements to AHMAC.
2. The implementation and maintenance of formalised communication and engagement mechanisms.
3. The development and implementation of a formal PCIF workplan.

Capacity and Capability

Goals

Goal 5:
To build and enhance the capacity of all relevant sectors in health and human services to provide quality palliative care.

Action Areas

Action will be undertaken to:

1. Identify and recommend improved funding models that explicitly promote flexibility to meet the needs of the patient and their family. This may include:
    - Funding based on assessed need
    - Funded care packages, including rapid access / rapid response options
    - Fund holding by appropriate providers, including aged care services, to be able to navigate and source appropriate care regardless of location, outside the aged care assessment process.
2. Explore new and enhanced roles for aged care providers in palliative care.
3. Undertake further research and ongoing monitoring of the relative cost of care and cost effectiveness of care models in the last year of life, particularly savings to be gained through appropriate hospital avoidance for clients approaching the end of their life.
4. Undertake further work to identify, classify and cost specialist palliative care clients and their care.
5. Provide enhanced, coordinated support for carers, volunteers, communities of carers and carer respite.
6. Provide coordinated, flexible local care delivery for people at the end of life regardless of where they live and address any barriers.
7. Further improve the skill and confidence of the generalist workforce to work with people with palliative care needs.
8. Enhance online palliative care support and resources through the development of ‘communities of interest’.
9. Promote the existence of online palliative care resources to all health and human service providers with links to service specific and disease specific websites.

Capacity and Capability, Continued

Action Areas (continued)

10. Work with Health Workforce Australia to ensure adequate numbers of skilled palliative care specialist providers across all disciplines.
11. Work with the Community Services and Health Industry Skills Council to include end of life and palliative care competencies in all care worker training packages.
12. Enhance and legitimise the role of specialist consultancy services in providing direct clinical advice, education and training, advocacy for end of life issues and training places.
13. Work with National eHealth Transition Authority and other relevant agencies to ensure that the capacity exists to record and track Advance Care Planning within electronic health records and appropriate systems.
14. Work with private health insurers to develop sustainable models of quality palliative care in the private sector.
15. Continue to develop the role of the general practitioner in palliative care through supportive approaches including:
    - the development of those with a special interest
    - the development of practice nurse roles in palliative care
    - incorporation of Advance Care Planning in enhanced primary care planning
    - appropriate support for general practitioners who are providing an active role in a client's palliative care, including providing telephone support and home visits.

Measures of Success

Measures of success for this goal will include:

1. Adequate skilled workforce to meet the needs of people with palliative care needs in a variety of settings.
2. Greater evidence of more people being able to have a choice as to where they are cared for.
3. Availability of cost of care data.
4. Recommend improved funding models.

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Glossary

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

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

End of life

The international definition is 'last two years of life'. By comparison, the term used in the Northern Territory is 'the final days'. The average time people are on end of life care is 37 hours.

Palliative care

Defined by the World Health Organization as:

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 or 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 patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, 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.

Palliative approach

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.