

## section 1.1: definitions

### palliative care

Palliative care is care provided for people of all ages who have a life limiting illness, with little or no prospect of cure and for whom the primary treatment goal is quality of life.<sup>1</sup> Access to palliative care is independent of diagnosis, age, cultural background or geography.

The World Health Organization defines palliative care to be “an approach which improves the quality of life of patients and their families facing life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial and spiritual problems.”<sup>2</sup>

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 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.<sup>3</sup>

### a palliative approach?

A palliative approach is delivered by primary health care providers in order to improve the quality of life for patients with a life limiting illness and their family and caregivers. Key points include:

- primary health care providers include generalist and specialist medical and nursing services in acute care hospitals, staff of residential aged care facilities, General Practitioners and community nursing staff
- this approach is active and focuses on comfort and reducing suffering and broad in its consideration of the patient as a “whole person”
- aims to help patients feel in control of their decisions for treatment and care
- pays close attention to their quality of life and their needs for grief and bereavement support
- clinical priorities include:
  - active attention to management of pain and other distressing symptoms
  - provision of physical, psychological, social, spiritual and practical support and involvement of the whole team of health care professionals including medical specialists and other doctors, nurses, allied health workers, chaplains and volunteers
  - assistance with complex decision-making
  - coordination of care across the varied settings in which health care is provided

Specialist palliative care services build on the work of primary health care providers with consultative support for palliative patients, their families and the staff in acute and community based settings on an “as required” basis.

## **palliative care – additional facts**

- Approximately 130,000 Australians die each year<sup>4</sup> – of these approximately 64,000 die from an “expected death” due to a terminal illness (a progressive illness for which there was no cure)
- 1 in 3 Australians have had someone close to them die from a terminal illness in the last 5 years
- 1 in 10 Australians were involved in direct care for that person
- 1/3 of patients whose death is expected are seen by specialized palliative care services<sup>5</sup>

## **who can have palliative care?**

A palliative approach is for anyone who has a life limiting illness whose disease is expected to cause the death of the patient within a foreseeable future.

Most people receiving palliative care have cancer, however others may suffer from end-stage non-malignant disease. Whilst the majority of people requiring palliative care are older, it is as important and valuable for young adults, adolescents and children.<sup>6</sup>

## **diseases most frequently encountered include:**

Cancer	End stage organ failure
Neuro-degenerative diseases	- end stage respiratory diseases
- Motor neurone disease	- end stage heart disease
- Parkinson’s disease	- end stage kidney disease
- Huntington’s disease	- end stage liver disease
HIV/AIDS	Cystic fibrosis
Advanced dementia	Children with progressive neurological conditions

Palliative care is more than care at the very end of life; it is a way of positively influencing the course of a patient’s illness and their quality of life throughout that illness.

## **who is the palliative care team?**

The team usually comprises:

- the patient
- caregivers (family, friends and other supportive networks)
- Primary health care professionals (General Practitioner, community nurses and allied health professionals)
- Medical specialists such as cardiologists, medical oncologists, surgeons
- Palliative care specialist services provide support and input for these teams when patient, caregiver or primary health professionals needs exceed the capacity, skills or resources available.

The team may also include pastoral care workers, social workers, volunteers, cultural advocates and proxy decision makers. Each team involved in the patient’s care will be a different one and aims to match, as far as possible, the identified needs of the patient.

Every patient facing a life limiting illness needs a unique palliative care team, which in many cases may not require the involvement of a palliative care specialist service.

## **acknowledging the need for support across the settings of palliative care**

Palliative care is delivered, where possible, where the person chooses.

### **▪ in acute hospital settings and hospices**

Staff in the acute care wards of hospitals play an essential role in providing a palliative approach to a diverse range of patients, whether they are acute medical or surgical areas, intensive care units or emergency departments. Specialist palliative care services in the metropolitan region offer support to acute care staff through a variety of services including consultancy into the major hospitals, outpatient clinics and specialist inpatient care either in the acute hospital or in a discrete hospice. Support also takes the form of regular education and involvement in research to inform best practice.

### **▪ in the community (in patients' homes and in residential care)**

In Australia, palliative care is most often provided for patients in the last three to six months of life<sup>7</sup>, with up to 90% of terminally ill patients spending the majority of their last year of life at home.<sup>8</sup> Settings of care include the patient's home, which may be a private residence or an aged care facility or another supported living environment and day care or respite support facilities.

Providing palliative care at home can be a complex task and is not possible for many people without the support of caregivers.<sup>9</sup> Caregivers require practical, physical, financial and emotional support in order to sustain their unpaid caring role- a role which may have a significant impact on their employment, their own health and social opportunities.<sup>10</sup>

The importance of ready access to information about supports available to caregivers is clear, as is a coordinated approach to accessing services in a timely manner.

Specialist palliative care services also play a role in supporting primary health care providers, including General Practitioners and community nurses in both metropolitan and rural settings and staff in residential aged care and other supported facilities. This may be through advice, clinical review and assessment or support in care planning.

### **▪ in the workplace**

Practical and useful information for people facing a life limiting illness, the caregivers for those with a life limiting illness and the work colleagues of these patients and caregivers who continue to work either during their illness and treatment or in conjunction with their caring role is available at the [www.livingcaringworking.com](http://www.livingcaringworking.com) website.

## **related resources and information:**

**Living Caring Working** website <http://www.livingcaringworking.com/>

- provides palliative care information, access to evidence-based literature, research resources and news on what's happening in palliative care for clinicians, researchers and educators.

**Palliative Care Australia** see <http://www.pallcare.org.au/>

- the national peak body for palliative care who provide publications of national guidelines and research studies and press releases related to palliative care delivery and community awareness.

## references

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- <sup>1</sup> Standards for Providing Quality Palliative Care for all Australians (2005) Palliative Care Australia, ACT.
- <sup>2</sup> World Health Organisation Definition of Palliative Care (2004).
- <sup>3</sup> World Health Organisation Definition of Palliative Care (2004).
- <sup>4</sup> Palliative Care Australia- E-bulletin, Issue 2, Nov/Dec 2006, quoting figures from the Australian Bureau of Statistics, 30 November 2005.
- <sup>5</sup> Palliative Care Australia- The facts- media release- 21 May 2006.
- <sup>6</sup> National Palliative Care Strategy. A National Framework for Palliative Care Service Development (2000). Commonwealth of Australia.
- <sup>7</sup> Kellehear, A. (2001). The changing face of dying in Australia. *MJA* 175 (10): 508-510.
- <sup>8</sup> Palliative Care Australia (1999). *State of the Nation 1998 - Report of the National Census of Palliative Care Services*. Palliative Care Australia, Yarraluma.
- <sup>9</sup> Hudson, P. (2003). Home-based support for palliative care families: challenges and recommendations. *MJA*, 179: S35-S37.
- <sup>10</sup> The Hardest Thing we have ever done: The social impact of caring for terminally ill People in Australia. (2004). Palliative Care Australia.