

CARERS AND END OF LIFE

Interim Position Statement

As considered by Palliative Care Australia Council on 10 October 2008 and 1 December 2008, and Palliative Care Australia Executive on 2 December 2008

Final draft for consideration by PCA member organisations and for public comment



**Palliative
Care
Australia**

Palliative Care Australia is the national peak body established by the collective membership of eight state and territory palliative care organisations and the Australian and New Zealand Society of Palliative Medicine. 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.¹

Palliative Care Australia believes

- Dying is part of life. The care of people at the end of life, their families and carers is the responsibility of the whole community.
- Carers must be recognised as *both a key partner* in the care team *and a recipient of care* in accordance with the palliative care service provision model.
- Enabling people's preferences to receive quality care at the end of life in the setting of their choice is dependent upon ongoing physical, emotional, practical and spiritual support from individual carers and their communities as well as health professional support.
- The extent and quality of support provided to the carer and the person nearing the end of life is a key determinant of both of their experiences. The whole community should support them.
- As a community we can and must do better in supporting carers by developing the foundations of a *carer-supportive social system* that provides the necessary support to enable carers to provide care in a manner that also promotes their health, wellbeing and personal aspirations.

Palliative Care Australia calls for

- The role of carers in providing and enabling quality care for people nearing the end of life to be *recognised and valued* by society.
- Provision of greater information and support to carers and to patients to enable them to access health care and carer support services, aided by greater links between services.
- Commitment to developing the foundations of a *carer-supportive social system* that supports and enables carers by:
 - providing improved access to timely *in-home support* (including services, equipment, information, education and resources);
 - developing and implementing best practice models for delivering nationally consistent *carer education and training*;
 - providing expanded access to *respite care* services to support carers;
 - promoting the *health and wellbeing of those caring for people at the end of life* by educating primary health

¹ The following definitions of end of life, end of life care and palliative care are used throughout this position paper. Source: Palliative Care Australia, *Palliative and End of Life Care - Glossary of Terms*, PCA, Canberra, 2008.

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 the people requiring care.

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.

care providers in the early identification of carers' emotional and physical health needs, including during bereavement; encouraging regular health checks for carers; and ensuring that carers have timely access to counselling services, including during bereavement;

- addressing carers' needs for greater *financial support*, and
- supporting participation of carers in the labour force through *carer-sensitive workplace policies* that support flexible working hours and leave arrangements for carers.

Background

There are close to 2.6 million carers, and nearly 500,000 primary carers in Australia,² providing close to 1.2 billion hours of care annually.³ Estimates suggest that carers provide 76% of all services to people needing care and support.⁴

The need for care within our communities is expected to increase with the ageing of our population. This is informed by the continuing increase in life expectancy of Australians and the accompanying changing nature of the last phases of life. Congruently, with the changing nature of causes of death and increased medical interventions, there are a greater number of Australians living out the final stages of their life with chronic, complex conditions.⁵ The pragmatic reality is that many elderly Australians may live extended periods of time with disability and as the recipients of informal care.

Associated with the increasing need for end of life care is an expected ongoing decline in the caregiver ratio. The ratio of primary caregivers to older persons needing informal care is estimated to drop from 57/100 to 35/100 in the next thirty years.⁶

Improved services such as respite are presently needed to support carers in their diverse roles.⁷ These services will need to be further upgraded and extended as the numbers of carers decrease in the future.

Needs-based service provision

In 2005, PCA endorsed a population needs-based approach to end of life care service development which articulated a plan for providing equitable access to end of life care while promoting effective and ethical use of resources⁸. PCA recognises population needs-based end of life care as a quality management approach that involves the evaluation of individual holistic needs of patients, their families and carers and provides for the coordination of appropriate care.

The 13 *Standards for Providing Quality Palliative Care for all Australians*⁹ define the standard of care that all Australians should be able to expect in different care settings. For the purposes of population needs-based service planning, all people at the end of life can be considered to fall within three broad subgroups – those whose care needs can be categorised as:

- complex, or
- intermediate, or
- appropriately addressed through primary care services.

Patients may need to move at different times between these subgroups. This should be as seamless as possible.

Carers and end of life care at home

An estimated 100,000 Australians die each year from an 'expected' death.¹⁰ Each of these Australians should be able to rely on a promise of access to quality care at the end of life that is based around meeting their needs and respecting their care preferences.

² Australian Bureau of Statistics, *Disability, Ageing and Carers, Australia*, cat. no. 4430.0, ABS Ausstats, 2003, retrieved 30 April 2008, <<http://www.abs.gov.au/AUSSTATS/abs@.nsf/Lookup/4430.0Main+Features12003?OpenDocument>>.

³ Access Economics, *The economic value of informal care: report prepared for Carers Australia*, 2005, retrieved 15 September 2008, <<http://www.accesseconomics.com.au/publicationsreports>>.

⁴ Palliative Care Australia (PCA), *The hardest thing we have ever done - the social impact of caring for terminally ill people in Australia 2004: Full report of the national inquiry into the social impact of caring for terminally ill Australians*, PCA, Canberra, 2004.

⁵ MJ Lewis, *Medicine and care of the dying: A modern history*, Oxford University Press, Oxford, 2007.

⁶ AMP National Centre for Social and Economic Modelling, *Who's going to care? Informal care and the ageing population*, Report prepared for Carers Australia, AMP.NATSEM, Canberra, 2004.

⁷ PCA, *the hardest thing we have ever done*, 2004.

⁸ PCA, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005.

⁹ PCA, *Standards for providing quality palliative care for all Australians*, PCA, Canberra, 2005.

¹⁰ There were 137,900 deaths registered in Australia in 2007. Australian Bureau of Statistics, *Deaths: Australia*, cat. no. 3302.0, ABS Ausstats, 2007, retrieved 30 April 2008 < <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/3302.02007?OpenDocument>>. The Australian Bureau of Statistics doesn't code cause of death data according to 'expected' and 'unexpected' deaths. This estimate of 'expected' death rates is based on a basic analysis of ABS cause of death data for 2006 and subtraction of all assumed deaths that were accidental, resulted from suicide or could potentially be from acute illness. This figure is expected to be an underestimation.

Many Australians express a preference for their home to be the primary site of their end of life care if circumstances allow.¹¹ Supporting people's preferences to receive end of life care in their home is, in many cases, dependent upon ongoing physical, emotional and spiritual support from the community, and, most often, from individual carers.

Support and the caring experience

Caring for someone who is dying is an individual commitment and can be a rich, rewarding and challenging personal experience. Carers often express strong positive emotions about their care giving. Many describe an opportunity to express their love through caregiving and find significant meaning in their roles.¹²

The caring experience, however, occurs within a broad social context which is a key determinant of the quality of that experience. Carers' caregiving experience, health and wellbeing are inextricably linked to the availability and quality of the support they receive. Evidence attests that those fortunate to have sufficient support mostly reflect positively on their caring experience.¹³ Conversely, there is considerable evidence that ongoing caregiving adversely affects family caregivers who are not sufficiently supported and lack adequate resources in undertaking this complex role.¹⁴

Adequate support is not a reality for many carers. This is associated with physical, emotional and financial costs to their wellbeing. The largest survey of carers' health and wellbeing conducted to date found that carers have the lowest level of wellbeing of any population group.¹⁵ There is strong evidence suggesting that the physical health of carers can be adversely affected by adopting a carer role if sufficient support is not provided and that there is often a heavy emotional strain associated with caregiving at the end of life, with carers experiencing fatigue, resentment, social isolation and stress.^{16,17}

Care-giving is often associated with a negative impact on financial security and wellbeing. The primary caring role reduces a person's chances of being employed as caring commitments mean that some carers are unable to work, or have to work fewer hours or in a lower paid job.¹⁸ Limited employment opportunities for primary carers are reflected in their incomes, with over half reporting a government pension or allowance as their principal source of income.¹⁹ Lack of flexible working arrangements for those caring for someone who is dying or for those experiencing bereavement compound the stress often experienced by carers.²⁰

Care-giving may have an economic burden on carers in addition to the negative impact on their employment, with significant costs incurred through medication and health care costs, fees for community services and payments towards residential care and respite.²¹ There are also long-term financial impacts of caring, such as loss of superannuation and the ability to save for retirement or to realise personal aspirations or goals.²²

A carer both provides and needs support, yet the needs of carers are often overlooked. Carers frequently subordinate their own emotional and health needs beneath those they are caring for and these needs are frequently overlooked by health and care workers who are not trained to recognise them.²³

Research undertaken by PCA has identified that carers commonly have critical unmet information and education needs relating to their carer role.²⁴ Many carers are not equipped with adequate support, training and resources to enable them to carry out their end of life care responsibilities effectively. Capacity to meet needs directly impacts the quality of care received by the patient as well as the caring experience and quality of life of the carer.²⁵ There are currently no long-term, nationally consistent education and training packages for carers and limited infrastructure to maintain a sustainable education and training program.²⁶

Research undertaken by PCA suggests that many high intensity carers see respite care as the most important support service to promoting their health and wellbeing.²⁷ Access to respite care is disparate across the nation,

¹¹ GE Grande, JM Addington-Hall, and CJ Todd, 'Place of death and access to home care services: Are certain patients groups at a disadvantage?' *Social Science Medicine*, vol. 47, no. 5, 1998, pp. 565-579.

¹² PCA, *the hardest thing we have ever done*, 2004.

¹³ PCA, *the hardest thing we have ever done*, 2004.

¹⁴ PCA, *the hardest thing we have ever done*, 2004.

¹⁵ RA Cummins, J Hughes, A Tomyn, A Gibson, J Woerner, and L Lai, *Australian Unity Wellbeing Index, Survey 16.1, Special Report – Groups with the highest and lowest wellbeing in Australia*, Deakin University, Australian Unity Limited and Carers Australia, Melbourne, 2007.

¹⁶ B O'Connell, S Bailey, and A Walker, 'Promoting the health and well being of older carers: a proactive strategy', *Australian Health Review*, vol. 26, no. 2, 2003, pp. 78-86.

¹⁷ PCA, *the hardest thing we have ever done*, 2004.

¹⁸ Australian Bureau of Statistics, *Disability, ageing and carers: summary of findings*, cat. no. 4430.0, ABS, 1998.

¹⁹ ABS, *Disability, ageing and carers*, 1998.

²⁰ PCA, *the hardest thing we have ever done*, 2004.

²¹ PCA, *the hardest thing we have ever done*, 2004.

²² PCA, *the hardest thing we have ever done*, 2004.

²³ PCA, *the hardest thing we have ever done*, 2004.

²⁴ PCA, *the hardest thing we have ever done*, 2004.

²⁵ PCA, *the hardest thing we have ever done*, 2004.

²⁶ Carers Australia, *Submission to the National Health and Hospitals Reform Commission: Imagine a health system without family carers*, Carers Australia, Canberra, 2008, retrieved 15 September 2008, <http://www.carersaustralia.com.au/index.php?option=com_content&task=view&id=26&Itemid=103>.

²⁷ PCA, *the hardest thing we have ever done*, 2004.

frequently not available in 'emergency' situations or on a short notice, and respite places for palliative patients are often further limited due to specific care needs and eligibility criteria.

Carers and end of life care provision

Palliative care acknowledges the carer as both part of the care team and as a recipient of care and recognises that the needs of the carer do not stop with the death of their loved one, but include care and support to deal with bereavement and grief.²⁸ However, the capacity of primary care providers who may be supporting the carer in the provision of end of life care to identify and address carers' physical and emotional health needs is often inhibited by lack of awareness and education as well as systemic barriers.²⁹

²⁸ World Health Organisation, *WHO definition of Palliative Care*, 2008, retrieved 15 September 2008, <<http://www.who.int/cancer/palliative/definition/en/>>.

²⁹ CE Bulsara and N Fynn, 'An exploratory study of GP awareness of carer emotional needs in Western Australia' *BMC Family Practice*, vol. 1, no. 33, 2006.

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