



**Palliative
Care
Australia**

RESIDENTIAL AGED CARE AND END OF LIFE

Position Statement

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

- The provision of quality end of life care for all is most efficiently and effectively achieved in accordance with a *needs-based service delivery model* that acknowledges that patients have different needs that may change over time. There needs to be strong networks between residential aged care facilities and primary and specialist care providers, as well as support care providersⁱⁱ and the community.
- End of life care should be recognised as part of the normal scope of practice of residential aged care, recognising that aged care facilities are home for many people at the end of life.
- End of life care should be considered a *core competency* for aged care workers.
- Aged care services must develop and implement workforce and service development plans that acknowledge their end of life care responsibilities.
- The implementation of needs-based end of life care should be informed by *standardised referral criteria* that outline the requirements for upward and downward referral relevant to aged care, primary health care and specialist palliative care.
- More needs to be done to make residential aged care facilities culturally sensitive to the care needs of people with terminal conditions.
- There are barriers, including inadequate pain relief and symptom management, in residential aged care facilities preventing people being able to receive quality end of life care.

Palliative Care Australia calls for

- End of life care to be acknowledged as a basic competency for aged care workers (regardless of the setting in which they work) and included in the *core curricula of aged care worker education* and as an element of ongoing training.
- The development and implementation of *nationally standardised referral criteria* for patients with palliative care needs that promote needs-based service provision, supported by a national roll-out/education campaign.
- Aged care services, including residential aged care facilities, to develop and implement *workforce and service development plans* that acknowledge their end of life care responsibilities as part of needs-based service provision. This is likely to require increased levels of staffing with practitioners who can prescribe and administer pain and symptom management drugs.
- The introduction of *systems for coordinating the management of pain and symptom relief* for residents in residential aged care facilities that address limitations in who can prescribe and administer medication to ensure residents' care needs are met in a timely and ongoing manner.
- Full integration of the National Palliative Care Standards with the Aged Care Accreditation Standards.

- The implementation of measures to *address workforce shortages* in aged care, and thereby their impact on aged care facilities' capacity to provide quality end of life care.
- Increased recognition of specialist palliative care and its role in supporting primary care provision of needs-based end of life care, through direct, indirect or consultant care.

Background

The significance of our ageing population to aged care, and to the demand on such services for end of life care, is substantial and will increase with the expected increases in the proportion of the population aged over 65 years. In 1999, 12% of our population was over 65 years of age and 2% was over 80 years. It is predicted that by 2016, 16% will be over 65 years and 4% will be over 80 years, increasing by 2041 to 25% over 65 years and 8.3% over 80 years.ⁱⁱⁱ For dementia alone the "epidemic" affecting an estimated 162,000 people in 2002 is expected to affect over half a million Australians by 2040.^{iv}

Residential aged care facilities are increasingly the place of death for people with terminal conditions, unless residents are transferred to acute care facilities.

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 resources^v. 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 involves the coordination of appropriate care.

The 13 *Standards for Providing Quality Palliative Care for all Australians*^{vi} 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 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.

Access to, and the quality of, palliative care is diverse and inconsistent in residential aged care. Some aged care facilities enjoy ready access to primary care physicians well skilled in palliative care and to specialist palliative care physicians. Some facilities, particularly high care facilities, have systems in place to limit hospitalisations by providing care in-place.

Supporting aged care facilities to work towards providing quality end-of-life care will require aged care facilities to be additionally resourced to provide appropriate palliation, pain and symptom relief.

This will include: appropriate access to general practitioners, to palliative care specialists under agreed and consistent referral and access criteria, and to nurses who can administer opioids. It will also include access to PBS-subsidised palliative medicines for residents of aged care facilities, and the structuring and resourcing of specialist palliative care services so that they are able to provide care and consistent support for primary health care providers in the residential aged care setting.

The *Guidelines for a Palliative Approach in Residential Aged Care*, were launched in 2004 and distributed to every aged care home in Australia to help aged care team members to apply a palliative approach in residential aged care facilities. An Enhanced Version was issued in May 2006 after approval by the National Health and Medical Research Council.^{vii}

PCA has been involved in substantial projects implementing the *Guidelines*, including a Resource Kit, assisting the development of training resources for Certificate III and Certificate IV competency units in a palliative approach, ongoing production of the Residential Aged Care Palliative Approach Network (RACPAN) Newsletter, and working with the Australian General Practice Network and Divisions of General Practice on the *Engaging GPs' Support for the Implementation of the Guidelines for a Palliative Approach in Residential Aged Care* project.

Reference list

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Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005. Available at: <<http://www.palliativecare.org.au/Portals/46/resources/PalliativeCareServiceDevelopment.pdf>>.

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Palliative Care Australia, *Palliative and End of Life Care – Glossary of Terms*. PCA, Canberra, 2008. Available at: <<http://www.palliativecare.org.au/Portals/46/resources/PCA%20Glossary%20Final%20July%202008%20LR.PDF>>.

ⁱ 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.

ⁱⁱ Support care providers include assistants in nursing and personal care staff in aged care homes, volunteers, charitable organisations, complementary 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. Source: Palliative Care Australia, *Palliative and End of Life Care – Glossary of Terms*, PCA, Canberra, 2008.

ⁱⁱⁱ J Abbey, 'The reality for aged and community care and end of life'. Presentation to *A Matter of Life and Death: Confronting the new reality*, Canberra, March 2008.

^{iv} *ibid.*

^v Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005.

^{vi} Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, PCA, Canberra, 2005.

^{vii} National Palliative Care Program, *Guidelines for a Palliative Approach in Residential Aged Care (APRAC Guidelines)*, Enhanced Version approved by National Health and Medical Research Council, Australian Government Department of Health and Ageing, Canberra, May 2006, retrieved 15 September 2008, <http://www.nhmrc.gov.au/publications/synopses/_files/pc29.pdf>.