



**Palliative
Care
Australia**

PRIMARY HEALTH 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.
- 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.
- End of life care is, and should be, part of the normal scope of practice of all primary health care professionals.
- End of life care should be considered a *core competency* for all primary health care workers.
- Health service *workforce and service development plans* should be developed in collaboration with other care providers to support needs-based service provision.
- 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.
- Discussion and reform towards a *primary health care system that enables broader access to quality end of life care* through increased capacity of primary health care providers should be actively supported.
- More needs to be done to make primary health care culturally sensitive to the care needs of people with terminal conditions.
- There are barriers, including inadequate pain relief and symptom management, 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 core competency for primary health care workers and included in the core curricula of health worker education and as an element of ongoing training.

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 (PCA), *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.

- The implementation of needs-based end of life care for patients with palliative care needs should be informed by *nationally agreed criteria* for access and referral to, and discharge from, specialist palliative care services. The nationally agreed criteria should promote needs-based service provision, and be supported by a national roll-out/education campaign.
- Health services should be supported in developing and implementing *workforce and service development plans* that acknowledge the end of life care responsibilities of primary care providers as part of needs-based service provision.
- *Recognition of specialist palliative care* and its role in supporting primary health care provision of needs-based end of life care, through direct, indirect or consultative care.
- The introduction of research and data collection methods to help improve the quality of care by primary health care professionals in serving the end of life population.

Background

The capacity of the current health system to provide access to quality care at the end of life for all Australians who may require it is questionable.² As the Australian population continues to age and an increasing number of Australians live out the final stages of their life with chronic, complex conditions, both the total population, and the proportion of the Australian population requiring end of life care annually, is expected to increase. This underlines the necessity of developing an approach to end of life care that prioritises quality care and promotes broad access through the efficient use of resources.

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 resources.³ 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*⁴ 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.

At the centre of the needs-based approach to care provision is an acknowledgement of heterogeneous care needs at the end of life and a recognition that the end of life needs of many patients are appropriately met by primary care providers (generalist, and other specialist and support care), with specialist palliative care providers contributing direct, indirect care or consultation advice as required.⁵

The role of primary care providers is outlined within this needs-based framework. Primary care providers include the patients' primary generalist providers who are normally the first contact medical, nursing or allied health professional. The primary generalist provider has an ongoing role in the care of patients with an eventually fatal condition. Primary specialist providers include all other specialists that have first contact with patients.⁶ In general, the substantive work for both these groups is not palliative care.

The largest subgroup includes those patients who do not require access to specialist care as their needs may be met through their own resources or with the support of primary care providers.⁷

The second largest subgroup of patients may experience sporadic exacerbations of pain or other physical

² Palliative Care Australia, *End of life care is everyone's affair - tackling the challenge of end of life: Palliative Care Australia submission to the National Health and Hospitals Reform Commission*, PCA, Canberra, 2008.

³ Palliative Care Australia, *A Guide to Palliative Service Development: A population based approach*, PCA, Canberra, 2005.

⁴ Palliative Care Australia, *Standards for providing quality palliative care for all Australians*, PCA, Canberra, 2005.

⁵ Palliative Care Australia, *Palliative and End of Life Care - Glossary of Terms*, PCA, Canberra, 2008.

⁶ *ibid.*

⁷ Palliative Care Australia, *A Guide to Palliative Service Development*, 2005.

symptoms or may experience complex social or emotional distress. This temporary increase in their level of need may require access to specialist palliative care services for consultation and advice, however the needs of this population group can be met by their primary care provider working in consultation with a specialist palliative care provider.

The smallest subgroup of patients are those who have ongoing complex physical, social, psychological and/or spiritual needs that do not respond to simple or established protocols of care. They usually require highly individualised care plans developed, implemented and evaluated by knowledgeable and skilled specialist practitioners, in partnership with primary care providers.

Primary care providers need to manage the care of their patients with a terminal condition, and to work in consultation with specialist palliative care providers to meet the needs of patients whose end of life care needs may be more complex (PCA, 2005). This necessarily requires primary care providers to have adequate skills, training and education and established relationships with specialist palliative care providers.

End of life care as a core education requirement for primary care providers

A key element in providing quality needs-based end of life care is ensuring that those involved in the provision of end of life care, whether as primary or specialist palliative care providers, are equipped with the skills and resources to perform their roles effectively.

The role of primary care providers includes assessment, triage, clinical management, referral specialist palliative care providers where appropriate, and care coordination using a palliative approach for patients with end of life care needs.⁸ Primary care providers thus require, as a core skill, the capacity to perform this role effectively.

In recent years the end of life care educational requirements of primary care providers have been increasingly acknowledged, most notably by the Palliative Care Curriculum for Undergraduates (PCC4U) Project, and projects designed to promote competency in end of life care among currently practising primary care workers in the aged care sector. The reach of these projects to date has been, understandably, limited. Notably, however, the PCC4U Project represents both a recognition of the necessity of undergraduate education in end of life care for all primary health care professionals, as well as steps towards achieving this goal. This project has been explicit in outlining the palliative care capabilities required by primary care health providers:

- effective communication in the context of an individual's responses to loss and grief, existential challenges, uncertainty and changing goals of care
- appreciation of and respect for the diverse human and clinical responses of each individual throughout their illness trajectory
- understanding of principles for assessment and management of clinical and supportive care needs
- the capacity for reflection and self evaluation of one's professional and personal experiences and their cumulative impact on one's self and others.⁹

Development of nationally agreed referral and discharge criteria

As noted above, the needs-based approach to end of life care offers a framework based on resource efficiency and delivery of quality care. At least in part, this is contingent on effective assessment and referral practices on behalf of primary care providers to ensure that individual patient's care needs are met in a timely manner. In this sense a key component of effective needs-based service provision is the development of protocols that establish referral and assessment criteria.

The necessity of establishing nationally agreed referral and discharge criteria to ensure responsive, evidence-based care that meets patients' needs has been underlined by research demonstrating disparity and uncertainty over when referral to a specialist palliative care provider is required and warranted. Auret, Bulsara and Joske¹⁰, for example, studied Australasian haematologists' referral patterns to palliative care, finding variation between providers in when referral occurred. Further, they found widespread referral practices that do not support needs-based service provision. Johnson et al¹¹ assessed cancer specialists' (including haematologists') palliative care referral practices. They concluded that "measures are needed to encourage ongoing needs-based assessments, especially of emotional, cultural and spiritual issues."

⁸ Palliative Care Australia, *A Guide to Palliative Service Development*, 2005.

⁹ Palliative Care Curriculum for Undergraduates Project Team, *Principles for including palliative care in undergraduate curricula*, Australian Government Department of Health and Ageing, Canberra, 2005.

¹⁰ K Auret, C Bulsara, and D Joske, 'Australasian haematologists' referral patterns to palliative care: lack of consensus on when and why', *Intern Med Journal*, vol. 33, no. 12, 2003, pp. 549-51.

¹¹ CE Johnson, A Girgis, CL Paul, and DC Currow, 'Cancer specialists' palliative care referral practices and perceptions: results of a national survey', *Palliat Med*, vol. 22, no. 1, 2008, pp. 51-7.

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