

CRANAplus Position Statement Palliative Care

This position statement was developed in collaboration with, and is endorsed by, Palliative Care Nurses Australia (PCNA).

Palliative Care is an approach to care that improves the quality of life of people facing life-threatening or life-limiting illness, regardless of location or care setting. The essence of palliative care is to provide comfort through the prevention, early detection of pain, and other physical, social, psychological and spiritual needs. A holistic approach is required to assist the individual and their families to adapt to their changing needs, with specific emphasis on the psychosocial, spiritual aspects of dying and bereavement.

It is well acknowledged that people living in remote and isolated areas have higher levels of illness and chronic conditions. They are often not well served by support services and specialist palliative care networks.

Palliative care in isolated areas is often delivered and coordinated by generalist nurses and doctors, with minimal access to a palliative care specialist, physicians or nurses or the array of allied health professionals that is afforded to people receiving end of life care in more populated urban or regional environments.

Aboriginal and Torres Strait Islanders account for 2.5% of the total Australian population, yet approximately 60% of the remote population, and have significantly poorer health outcomes compared with the Australian population. Aboriginal and Torres Strait Islander people tend not to frequent palliative care services in mainstream facilities; and there is very little data to show their admissions to palliative care services (O'Brien *et al.* 2013).

Cultural respect and cultural safety are essential elements when addressing 'end of life' needs with Aboriginal and Torres Strait Islanders, and others from different cultural backgrounds within Australia's remote and isolated communities. The desire to die at home or on traditional homelands may be an essential element to the provision of palliative care for some people.

CRANAplus believes

All remote healthcare providers are guided by the Australian Palliative Care Standards (2018) that shape their practices to provide safe, quality care for individuals and their families.

People facing life-threatening or life-limiting illness have a right to the care and choice of treatment, and access to specialist palliative care services input. Advance Care Planning and Advance Health Directives, are an avenue for individual's to clearly make known their wishes when they can no longer exercise their right to make choices about their care, or consent to treatment.

There are many challenges for the delivery of quality palliative care services to remote and isolated communities as they have limited access to: specialist investigations and treatments; medical and allied health professionals; equipment; medications; home support; transport and accommodation; and respite care. In minimising these challenges, residing nurses/midwives, and Aboriginal and Torres Strait Islander healthcare practitioners/workers are pivotal in coordinating interprofessional collaboration amongst practitioners.

Telehealth is an expedient way of accessing timely advice and support for staff, the individual and their families, but does not remove the requirement for remote health professionals to maintain ongoing professional development and contemporary practice in palliative and end of life care.

CRANaplus recommends

Remote health services adopt and implement the Australian Palliative Care Standards (2018), which guide and shape the provision of palliative care to individuals living with a life-threatening or life-limiting illness.

People who have palliative care needs in remote and isolated, and rural locations have the right to:

- choose the location for their 'end of life' and have that choice respected
- access palliative care specialists and/or expert input/consultation, if their care needs cannot be managed by their local care team.
- access timely evidence-based pain and symptom management
- their psychosocial, spiritual and bereavement needs being met in a culturally safe manner
- have access to bereavement care, information and support services for their caregiver/s and family.

Remote healthcare providers be required to have a sound knowledge of palliative care; Advance Care Planning and Advance Health Directives, culturally diverse grief and bereavement needs, and pain management as part of their training and continuing professional development.

Remote health services be supported to develop the palliative care capacity of nurses/midwives, Aboriginal and Torres Strait Islander healthcare practitioners/workers, counsellors and other health professionals, to provide appropriate information and support for the individual, their families and wider community.

Significant resources be invested in the remote health sector to adapt existing services, or develop/link with new palliative care services, to ensure all remote and isolated communities receive optimal and culturally appropriate evidence-based treatment, services and support.

Smart use of technology including Telehealth needs to be freely available to enable connectivity between healthcare workers, and better access to palliative care advice and services.

CRANaplus commits to

Promote the importance of, and ensure easy access to appropriate preparation and ongoing palliative care education for the remote health workforce. Thereby enhancing their capacity in the early detection of pain, symptom control and physical, social, psychological, spiritual needs.

Promote awareness of the challenges in accessing locally appropriate palliative care services to support individuals and their families who reside in remote and isolated areas of Australia.

Advocate for innovative palliative care services, and/or new models of care, including formal linkages with larger regional palliative care services, which improve the quality of life for remote and isolated people facing life-threatening or life-limiting illness.

Actively participate in consultative processes with government and non-government organisations to address the many challenges associated with people living in remote and isolated communities accessing palliative care services; Build the palliative care capabilities of the remote and isolated workforce; and advocate the development of health policy and funding that improves access to palliative care in remote areas.

Australian Palliative Care Standards (2018)

Standard 1

Initial and ongoing assessment incorporates the person's physical, psychological, cultural, social and spiritual experiences and needs.

Standard 2

The person, their family and carers work in partnership with the team to communicate, plan, set goals of care and support informed decisions about the care plan.

Standard 3

The person's family and carers needs are assessed and directly inform provision of appropriate support and guidance about their role.

Standard 4

The provision of care is based on the assessed needs of the person, informed by evidence and is consistent with the values, goals and preferences of the person as documented in their care plan.

Standard 5

Care is integrated across the person's experience to ensure seamless transitions within and between services.

Standard 6

Families and carers have access to bereavement support services and are provided with information about loss and grief.

Standard 7

The service has a philosophy, values, culture, structure and environment that supports the delivery of person-centred palliative care and end-of-life care.

Standard 8

Services are engaged in quality improvement and research to improve service provision and development.

Standard 9

Staff and volunteers are appropriately qualified, are engaged in continuing professional development and are supported in their roles.

RESOURCES

Program of Experience in Palliative Approach (workshops, placements, support and education)

<http://www.pepaeducation.com/>

Care Search – Palliative Care Knowledge Network

<http://www.caresearch.com.au/Caresearch/Default.aspx>

End of Life Directions for Aged Care (including support hotline)

<https://www.eldac.com.au/tabid/4889/Default.aspx>

The Advance Project (training package for advanced care planning and palliative care)

<https://www.theadvanceproject.com.au/tabid/5217/Default.aspx>

eviQ opioid calculator

<https://www.eviq.org.au/Login.aspx?ReturnUrl=%2fOpioidCalculator.aspx>

palliAGEDnurse (smart device app for nurses working in residential aged care and community care)

<https://www.palliaged.com.au/tabid/4351/Default.aspx>

Palliative Care Australia
<https://palliativecare.org.au/>

Palliative Care Australia - Sustainable access to prescription opioids for use in palliative care
http://palliativecare.org.au/wp-content/uploads/dlm_uploads/2019/05/PalliativeCare-Opioid-Position-Final.pdf

Palliative Care Nurses Australia Inc
<https://www.pcna.org.au>

Australian Indigenous Health InfoNet Palliative Care toolkit
<https://healthinonet.ecu.edu.au/learn/health-system/palliative-care/>

REFERENCES

Australian Government Department of Health and Ageing. (2018). *Aged Care Quality Standards*. Australian Government Department of Health and Ageing, Canberra.

O'Brien, A., Bloomer, M., McGrath, P., Clarke, K., Martin, T., Lock, M., Pidcock, P., van der Rie, P., and O'Connor, M. (2013). Considering Aboriginal palliative care models: the challenges for mainstream services. *Rural and Remote Health*, 13: 2339.

Gaudet, A., Kelley, M. and Williams, A. (2014). Understanding the distinct experience of rural interprofessional collaboration in developing palliative care programs. *Rural and Remote Health*, 14: 2711

Pesut, B., Hooper, B., Robinson, C., Bottorff, L., Swaatzky, R. and D'Alhusien, M. (2015). Feasibility of a rural palliative supportive service. *Rural and Remote Health*: 15: 3116.

Cancer Australia. (2015). *National Aboriginal and Torres Strait Islander Cancer Framework*. Cancer Australia, Surry Hills, NSW. Accessed 18/05/15 https://canceraustralia.gov.au/system/tdf/publications/national-aboriginal-and-torres-strait-islander-cancer-framework/pdf/2015_atsi_framework_1.pdf?file=1&type=node&id=4274

Palliative Care Australia. (2018). *National Palliative Care Standards* [5th Edition]. Accessed 20/05/19, <https://palliativecare.org.au/standards>

Palliative Care Australia. (2018) *Palliative Care Service Development Guidelines*. Accessed 20/05/2019 <https://palliativecare.org.au/quality>

Quill, T. and Abernethy, A. (2013). Generalist plus Specialist Palliative Care — Creating a More Sustainable Model. *New England Journal of Medicine*, 368(13): p. 1173-1175. Accessed 30/9/2015
http://www3.med.unipmn.it/papers/2013/NEJM/2013-03-28_nejm/nejmp1215620.pdf