



**Palliative
Care
Australia**

Improving access to quality care at the end of life for Aboriginal and Torres Strait Islander Australians

Endorsed by PCA Council on 18 November 2009 as an interim position statement for consultation

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 acknowledges Aboriginal and Torres Strait Islander peoples as indigenous peoples and respects their position as traditional custodians of the country known as Australia.

Palliative Care Australia believes

- Quality care at the end of life is realised when it is culturally appropriate to the particular needs of individuals and groups that includes families, kinships and tribes.
- Holistic palliative and end-of-life care embraces the physical, emotional, psychosocial, spiritual and cultural dimensions of human life.
- Aboriginal and Torres Strait Islander peoples are generally ambivalent toward western health care and under-represented in the palliative and end-of-life care patient population.²
- Aboriginal and Torres Strait Islander people use health care services reluctantly, and palliative and end-of-life care services rarely, due to a range of factors.³
- Aboriginal and Torres Strait Islander peoples are not averse to the principles of holistic family-centred models of care that underpin contemporary palliative and end-of-life care.
- The values of kinship, culture, community underpinning palliative and end-of-life care are consistent with Aboriginal and Torres Strait Islander values.
- Aboriginal and Torres Strait Islander peoples' view of 'health' is not only the physical wellbeing of an individual, but the social, emotional and cultural wellbeing of the whole community and includes the cyclical concept of life-death-life.
- The place of dying and death is culturally and spiritually significant for many Aboriginal and Torres Strait Islander peoples.⁴ The need to 'return to country' is very important for many Aboriginal and Torres Strait Islander people at the end of their lives.
- There is a disparity in health service provision between urban and remote areas.
- The heterogeneity of Aboriginal and Torres Strait Islander culture means models of care need to be flexible to address the specific needs of different cultural groups.
- Contemporary models of palliative and end-of-life care in Australia which are dominated by western traditions and the biomedical paradigm should integrate Aboriginal and Torres Strait Islander traditions, values and cultural practice relating to palliation and end-of-life transitions.
- palliative and end-of-life care services should respect the basic rights of Aboriginal and Torres Strait Islander peoples to have their cultures respected and have equity of access to the same level of services as other Australians.

- The consequences of culturally inappropriate care can include psychological distress and unnecessary suffering for Aboriginal and Torres Strait Islander patients, their families and carers.
- There is a need to acknowledge more openly our failures in providing quality end-of-life care that is culturally appropriate to Aboriginal and Torres Strait Islander Australians, and to develop strategies and programs that respect and accommodate the spiritual and cultural beliefs of Aboriginal and Torres Strait Islander peoples.
- Community-based local approaches to end-of-life care are generally preferred, which leads to a significant role for Aboriginal and Torres Strait Islander health professionals in the delivery of quality end-of-life care.
- It is imperative that non-indigenous health professionals develop culturally safe practice through education or training and appropriate engagement with local indigenous communities.
- Fundamental to culturally safe palliative and end-of-life care is that providers or practitioners understand the historical journey and its influence on the contemporary society of Aboriginal and Torres Strait Islander peoples.
- There is a need to understand that all Aboriginal and Torres Strait Islander communities in Australia have a common heritage of loss, and that for an individual close to death and for their family and community, the impact of the loss and grief is often compounded by earlier experiences.⁵
- There is a general lack of understanding among non-indigenous health professionals about the nature of grief and bereavement among Aboriginal and Torres Strait Islander communities.
- The following principles are an essential and practical starting point for moving forward in achieving quality in the end of life for Aboriginal and Torres Strait Islander Australians:
 - equity
 - autonomy and empowerment
 - trust
 - humane, non-judgmental care
 - seamless care
 - emphasis on living
 - cultural respect
 - collaboration.^{6,7}

Palliative Care Australia calls for

- Support for, and resourcing of, Aboriginal and Torres Strait Islander organisations and personnel planning the development of end-of-life care, to ensure culturally relevant requirements are addressed and preferences of patients, their families and the communities are considered.
- Support for the resourcing and general strengthening of the role of Aboriginal and Torres Strait Islander health workers and liaison officers who can connect health professionals and services with the necessary skills, experience and knowledge in the local community.
- A commitment by governments to education and training that builds the cultural competence and cultural awareness of Australia's health care workforce through undergraduate, postgraduate, vocational and continuing professional education, including:
 - significant investment by government to increase the number, qualification levels and professional registration of Aboriginal and Torres Strait Islander peoples in the health workforce
 - appropriate training and education about cultural perspectives relating to palliative and end-of-life care issues, in core curricula for all health workers and health professionals providing services to Aboriginal and Torres Strait Islander people

- inclusion of palliative and end-of-life related topics in the core curricula for Aboriginal health worker Certificate III and IV
- continuation of the Program of Experience in a Palliative Approach⁸ (PEPA) to build on or develop culturally appropriate education for Aboriginal and Torres Strait Islander Health Workers.
- A commitment by service providers to work with Aboriginal and Torres Strait Islander organisations, to develop models of palliative and end-of-life care services appropriate to meet the needs of Aboriginal and Torres Strait Islander peoples. This will require:
 - fostering the practice of “advance care yarning” and family case conferencing – involving the patients and broader family in decisions about culturally appropriate care
 - review of organisational policies that may hinder access to culturally appropriate palliative and end-of-life care
 - the development of organisational and service planning models which incorporate strategies and initiatives to address the identified equity and access issues which inhibit or prevent Aboriginal and Torres Strait Islander people from benefiting from end of life services
 - all services to provide ongoing workforce training on the issues affecting the delivery of appropriate services to Aboriginal and Torres Strait Islander people
 - the development and delivery of information in a culturally appropriate way to Aboriginal and Torres Strait Islander communities to increase understanding and knowledge of end-of-life services and practices.
- The development of equal partnerships through memorandums of understanding or similar means, between palliative and end-of-life care services and Aboriginal and Torres Strait Islander health and advocacy organisations and individuals.
- An increase in the availability and accreditation level of interpreters to communicate with the estimated 55,000 speakers of Aboriginal and Torres Strait Islander languages, many of who may have English as a second, third or even fourth language.⁹
- The development of culturally specific research on the nature of grief and bereavement in Aboriginal and Torres Strait Islander communities and the implications for this in the development of appropriate support services.

Background

Aboriginal and Torres Strait Islander peoples make up approximately 2.5% of the Australian population, of which 90% identify as of Aboriginal origin, 6% Torres Strait Island origin and 4% identify as both Aboriginal and Torres Strait Island origin.¹⁰

Chronic Disease and Mortality

The health profile of Aboriginal and Torres Strait Islander people is very different from that of other Australians. Aboriginal and Torres Strait Islander people have poorer life expectancy, higher infant mortality - three times that of the general population - and adult mortality that is most marked in early adulthood to middle age.

In contrast, the overall Australian population has one of the highest life expectancies in the world, relatively low infant mortality, and death rates for persons aged 35-44 and 45-54 years that are five times less than those recorded for Aboriginal and Torres Strait Islander people.¹¹

In 1999-2003, the three leading causes of death for Aboriginal and Torres Strait Islander people resident in Queensland, South Australia, Western Australia and the Northern Territory were diseases of the circulatory system, external causes of morbidity and neoplasms.¹² Appropriate palliative and end-of-life care can improve the end-of-life outcomes in the first and third of these diseases.

Among the factors identified as significant contributors to the high levels of morbidity and the early age of death of Aboriginal and Torres Strait Islander people are poor antenatal care, poor child health, chronic disease and a lack of access to appropriate health care. Other determinants include cultural dispossession, social dislocation, poverty, poor housing, poor access to good food, poor education and lack of

employment.¹³ There is also evidence to suggest that there is also a need to understand racism as a cause of ill health in Aboriginal and Torres Strait Islander people.¹⁴

Data show Aboriginal and Torres Strait Islander people access aged care services at a younger age, consistent with poorer health status and lower life expectancy. Of those admitted to permanent or respite residential care during 2003-2004, almost 29% were under 65 years of age, compared with fewer than 5% of other Australians. Of all Aboriginal and Torres Strait Islander people receiving Community Aged Care Packages at 30 June 2004, 46% were aged below 65 years compared with 8% among other Australians. Of all clients receiving home and community care, 18% of Aboriginal and Torres Strait Islander clients were aged 75 years or over compared with 57% of other clients.¹⁵

Culture

Aboriginal and Torres Strait Islander culture is dynamic, and diverse across the Australian continent, both between different cultural traditions, and between urban and non-urban locations.

The concept of cultural safety needs to underpin improvements in Aboriginal and Torres Strait Islander palliative and end-of-life care. Fundamental to cultural safety is acknowledgment of cultural assumptions, lived experiences, Aboriginal and Torres Strait Islander holistic concepts of health, and the historical context of ill-health, dispossession and racism. We must all be aware of these factors, our prejudices and the historical power disparities it reproduces in health service delivery.

Furthermore, 'The core essence of cultural safety is that the health professional understands their own cultural identity, and is aware of the impact their culture can have on another'.¹⁶

Communication

One major issue affecting our ability to provide palliative and end-of-life care is communication. A failure to understand or appreciate the cultural practices of Aboriginal and Torres Strait Islander peoples leads to inappropriate and inadequate health care.

Research has found 'Communication would improve if health professionals learned to listen to the [Aboriginal and Torres Strait Islander] story and let it shape the structure of their own biomedical perceptions. Both staff and patients need to recognise that their understandings come from their own backgrounds, and are therefore saturated in their own histories, languages and culture'.¹⁷

Collaboration is also a fundamental prerequisite in communication and building relationships which in turn underpin better Aboriginal and Torres Strait Islander palliative and end-of-life care service delivery.

Collaboration is crucial in planning and implementing strategies for change to produce optimum outcomes. This required collaboration between: staff and patients; staff from different disciplines and with different expertise; patients and their families, health workers and interpreters.¹⁸

Given the historical background of lack of trust by Aboriginal and Torres Strait Islander Australians in mainstream health services, particular attention is needed to foster and sustain respectful, honest, trusting and productive relationships between consumers and providers. Service delivery models may need adjustment in order to ensure all involved have the time and space to create such relationships.

Geographical challenges

Around 2% of Australia's population are Aboriginal and Torres Strait Islanders. However, in the Northern Territory nearly 24% of the population is represented by Aboriginal and Torres Strait Islander peoples with lower percentages in the more populated states of Western Australia, South Australia and Queensland. While the majority of this population lives on or near accessible highways, a minority live in remote areas that can be difficult to access. The provision of health care and palliative and end-of-life care in these areas can be challenging.¹⁹

Aboriginal and Torres Strait Islander people living in more rural and remote areas may have to travel to major centres for appointments and treatments. This may be their first time away from country.

For many Aboriginal and Torres Strait Islanders the principle of 'dying in place of choice' has a particular meaning. This is the concept of 'going home to country'. While logistically it may be enormously challenging for the patient, family and community to achieve, it has the potential to realise the greatest gain for patients, their families and communities at the end of life.

The extremely disadvantaged position of many Aboriginal and Torres Strait Islander people, particularly those living in some rural and remote communities, poses special issues in the delivery of palliative and end-of-life care. These include issues related to the storage of medications and compliance, and the need for care providers to be aware that multiple health problems are more common among Aboriginal and Torres Strait Islander people.

Workforce

Aboriginal and Torres Strait Islander people are under-represented in the health workforce and among those with higher education health qualifications. In 2004 it was estimated that to achieve the same proportion of Aboriginal and Torres Strait Islander people working as health professionals as non-indigenous people, it would require a further 2,000 Aboriginal Health Workers to be trained.²⁰

Aboriginal and Torres Strait Islander doctors, nurses, psychologists and social workers play an important role in palliative and end-of-life care. Aboriginal and Torres Strait Islander Home and Community Care (HACC) workers and Aboriginal Health Workers play a key role in providing appropriate community based care and in liaising with other health care professionals involved in planning and delivering end-of-life services.²¹ There is great need for more Aboriginal and Torres Strait Islander people working in these settings.

Information, education and training

There is an urgent need for the development and provision of palliative and end-of-life care education and training for Aboriginal health workers and for staff based in Aboriginal and Torres Strait Islander health care settings.

Education in cultural awareness and Aboriginal and Torres Strait Islander issues in palliative and end-of-life care, including bereavement care, should be provided to general practitioners, nurses and allied health staff as a specific module in undergraduate training and as ongoing professional development.²²

The provision of information sessions about palliative and end-of-life care in Aboriginal and Torres Strait Islander community settings is clearly important to assist in overcoming the misunderstandings which inhibit access to available services.

Local strategies

Aboriginal and Torres Strait Islander peoples have different cultures and histories and in many instances different needs. Nevertheless, both groups are affected by the problems that face them as unique Australians. The differences must be acknowledged and may need to be addressed by locally developed, specific strategies.²³

Local solutions must arise from within the local community, with local consultation and local engagement, for without ownership by the community, engagement and sustainable improvements in the quality of end-of-life care are not possible.

¹ The following definitions of end of life, end-of-life care and palliative care are used throughout this position paper.

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.

Palliative Care Australia, *Palliative and end-of-life care glossary of terms*, Palliative Care Australia, Canberra, 2008.

² K Sullivan, L Johnston, C Colyer, J Beale, J Willis, J Harrison & K Welsh, *National Indigenous palliative care needs study: final report*, Prepared for the Australian Government Department of Health and Ageing, Canberra, 2003.

³ *ibid.*

⁴ Prior, D. (2009). The meaning of cancer for Australian Aboriginal women; changing the focus of cancer nursing. *European Journal of Oncology Nursing*. 13: 280-286.

⁵ I Maddocks & R Rayner, 'Issues in palliative care for indigenous patients', *Medical Journal of Australia*, vol. 179, no. 6 supplement, 2003, pp. S17-S19.

⁶ (Adapted from) P McGrath & H Holewa, 'Seven principles for Indigenous palliative care service delivery: research findings from Australia', *Austral-Asian Journal of Cancer*, vol. 5, no. 3, 2006, pp. 179-186.

⁷ Resource Kit, 2004

⁸ The Program of Experience in the Palliative Approach (PEPA) is an initiative of the Australian Government Department of Health and Ageing, funded through the National Palliative Care Program.

⁹ Kimberley Interpreting Service, *Discussion paper: Indigenous language interpreting services*, Kununurra, 2004.

¹⁰ Australian Bureau of Statistic 2006

¹¹ B Pink & P Allbon, *The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples*, Australian Bureau of Statistics, Australian Institute of Health and Welfare, Canberra, 2008.

¹² National Rural Health Alliance, *The health of Aboriginal and Torres Strait Islander Australians*, National Rural Health Alliance, Canberra, 2006.

¹³ *ibid.*

¹⁴ Y Paradies, R Harris & I Anderson, *The Impact of Racism on Indigenous Health in Australia and Aotearoa: Towards a Research Agenda*, Discussion Paper Series: No.4, Cooperative Research Centre for Aboriginal Health, 2008

¹⁵ B Pink & P Allbon, *op. cit.*

¹⁶ S Fenwick 2001 in Australian Government Department of Health and Ageing 2004: 14)

¹⁷ A Cass, A Lowell, M Christie, P Snelling, M Flack, B Marrnganyin & Isaac Brown, 'Sharing the true stories: improving communication between Aboriginal patients and health care workers', *Medical Journal of Australia*, vol. 176, no. 20, 2002, pp. 466-470.

¹⁸ *ibid.*

¹⁹ P McGrath, *The development of an innovative model for Indigenous palliative care service delivery*.

²⁰ National Rural Health Alliance, *op. cit.*

²¹ K Sullivan et al, *ibid.*

²² *ibid.*

²³ National Aboriginal Community Controlled Health Organisation, *Our guiding principles*, National Aboriginal Community Controlled Health Organisation, Canberra, 2008, viewed 7 July 2009, <<http://www.naccho.org.au/aboutus/principles.html>>.