

Position Statement

Aboriginal and Torres Strait Islander Community-Based Palliative Care

Background

The unusually high level of loss through Sorry Business for Aboriginal and Torres Strait Islander people has been noted by many. The Australian Institute of Health and Welfare found that 42% of Aboriginal and Torres Strait Islander respondents indicated they had experienced the death of a family member or close friend within the past year.¹

The term ‘malignant grief’ is used by Professor Helen Milroy to describe the process of irresolvable, collective and cumulative grief over multiple generations that affects Aboriginal individuals and communities, causing them to lose function. In this respect, ‘the grief has invasive properties, spreading throughout the body. Many of Australia’s Aboriginal people eventually die of this grief’.²

Palliative care improves the quality of life of people, their carers, families and communities who are facing challenges associated with a life limiting illness, whether physical, psychological, social or spiritual. Quality palliative care helps people live their lives as

fully and as comfortably as possible. It responds to the holistic needs, experiences, preferences and service requirements of those people and their families and is not a stand-alone service. It regards dying as a natural and expected process with similarities to spiritual and cultural beliefs of some Aboriginal and Torres Strait Islander communities — of life as a continuum — Life-Death-Life.³

QAIHC, as the peak body for Aboriginal and Torres Strait Islander community-controlled health organisations, has the cultural knowledge and networks to ensure co-design of community-led palliative care is responsive to the needs of local communities. This Position Statement is drafted to better realise the value of both QAIHC co-design and future investment for palliative care services to be delivered by ACCHOs.

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1. Australian Institute of Health and Welfare. (2009, January). *Measuring the social and emotional wellbeing of Aboriginal and Torres Strait Islander People*. Cat. No. IHW24, <https://www.aihw.gov.au/getmedia/5b75be10-49ee-4d9c-baf0-5092936c585e/msewatsip.pdf?v=20230605180910&inline=true>
 2. Parker, R., & Milroy, H. (2014). Aboriginal and Torres Strait Islander mental health: An overview. In P. Dudgeon, H. Milroy, & R. Walker (Eds.), *Working together: Aboriginal and Torres Strait Islander mental health and wellbeing principles and practice* (pp. 25–38).
 3. Palliative Care Curriculum for Undergraduates. (n.d.), Activity 12: Palliative care is holistic and family-centred. PCC4U.org, https://pcc4u.org.au/learning/topics/topic2/t2_section5/t2_activity12/

QAIHC position

The majority of people who need palliative care would prefer to be managed at home, or in Community, so it is essential that palliative care be integrated as part of primary health care.⁴ It is not practical nor desired for specialist palliative care services to provide all palliative care services to patients. Emphasis needs to be given to the continuity of care, culturally appropriate quality care, and respect for the wishes of patients and families. These can be achieved through comprehensive primary health care services such as ACCHOs.

The framework for ACCHO-led community-based palliative care needs to consider:

- Culturally informed, valued and safe quality care
- Aboriginal and Torres Strait Islander community-led team-based care
- Family-centred care (QAIHC Member's Model of Care)
- Returning to Country — if possible and desired
- Grief and bereavement support for families and community.

Aboriginal and Torres Strait Islander culturally safe and quality palliative care

Culturally safe, quality care is determined by the person, their family and community. It is important for healthcare providers to ask about and understand the cultural and spiritual considerations of Aboriginal and Torres Strait Islander people when providing family-centred care. This may involve the use of traditional medicine, preferences on place of passing, or what language is used when discussing palliative care.

Services need to ensure that they do not diminish, demean, or disempower the cultural identity and wellbeing of an individual.⁵

Tools and resources need to be co-designed and created with Aboriginal and Torres Strait Islander communities to reflect their self-determination and cultural knowledge, to promote the availability of services and benefits to the quality of life of the individual, carers, family and community. Aboriginal and Torres Strait Islander Community-led team-based palliative care should be primarily provided by an ACCHO and its

team, including Aboriginal and Torres Strait Islander Health Workers, GPs and case managers, as well as the family and carers. Many people facing the challenges of not recovering/dying can be managed in community settings with the support of primary healthcare staff and access to specialist care from time to time. Accessing specialist services should not limit people's access to other services, including aged care, disability support services, and other wrap around services necessary to manage comorbidities.

4. World Health Organization. (2018, October). *Integrating palliative care and symptom relief into primary health care: A WHO guide for planners, implementers, and managers*. World Health Organization. <https://iris.who.int/bitstream/handle/10665/274559/9789241514477-eng.pdf?sequence=1>

5. Nursing Council of New Zealand. (2011). *Guidelines for cultural safety, the Treaty of Waitangi, and Maori health in nursing education and practice*. Nursing Council of New Zealand. <https://online.flippingbook.com/view/960779225/>

Case study — A First Nations man's palliative care⁶

Steve, an 84-year-old Aboriginal man, has recently been diagnosed with end-stage renal failure. His wife passed away two years ago, and he lives alone. He had to move away from Country to receive treatment and is feeling isolated and alone. He has a deep desire to spend time on, and to die, on Country.

He was supported by his local Aboriginal community-controlled organisation with the following strategies:

Domain	Support service	Role	Benefit
Physical	GP	Management and treatment of his endstage renal failure	Improvement in symptoms
Emotional	Aged care support services	Assistance with shopping and cleaning	Boost sense of independence and autonomy
Social	Yarning circles	Regular meetings to connect with other people his age, or with similar diagnoses in the community	Increased connectedness to community
Cultural	Health workers with palliative care training	Advocate for Steve to visit his country and to put in place arrangements for him to die on Country when the time comes	Improvement in social and emotional wellbeing
Spiritual	Community	Encouraging Steve to be a cultural mentor to young men and to pass on his cultural knowledge	Increased connectedness to community, as well as benefits to the community

Aboriginal and Torres Strait Islander Model of Care is family-centred care

Holistic palliative care is designed around the wellbeing of the patient and their family, with a focus on not just physical wellbeing, but also emotional, social, cultural, and spiritual wellbeing.

Family-centred care involves holding the person, family and community in the highest regard and providing care that demonstrates respect for cultural practices and beliefs before, during and after passing.⁷

It is important to recognise, and to advocate for, Aboriginal and Torres Strait Islander kinship systems that extend beyond immediate family members. People need to be asked who they would like to be involved in discussions about their health care, and specifically in the end-of-life phase.

6. Commonwealth of Australia. (2017). *National strategic framework for Aboriginal and Torres Strait Islander peoples' mental health and social and emotional wellbeing 2017–2023*. Department of the Prime Minister and Cabinet. https://www.niaa.gov.au/sites/default/files/documents/publications/mhsewb-framework_0.pdf
7. McGrath, P., and Holewa, H. (2006). *Seven principles for Indigenous palliative care service delivery: research findings from Australia* (Version 1). CQUniversity. <https://hdl.handle.net/10018/6715>

Returning to Country for Aboriginal and Torres Strait Islander people, families, and communities

The place of death is culturally and spiritually significant for many Aboriginal and Torres Strait Islander people. All people should be able to choose their place of passing and have the option of returning home, to their family or to Country.⁸ The use of high-risk medications and equipment may pose a challenge to those who live in rural and remote communities, as well as the lack of specialist services in these areas.⁹

ACCHOs need to be supported by specialist palliative care services to address these challenges and provide culturally appropriate end-of-life care to their patients.

Grief and bereavement support for Aboriginal and Torres Strait Islander people, families and communities

Support is essential for not only the person coming to terms with the end-of-life phase, but also for their carers, families and communities. Grief is a simple word that describes the natural but often complex reactions experienced after an important loss. All people experience grief differently, with it manifesting emotionally, mentally and/or physically, as well as potentially impacting on behaviour and spiritual beliefs.

Families and communities that experience multiple people passing over a short period can be grieving for more than one person at a time. This is not uncommon and can cause grief to build. Caring for someone in the end-of-life phase can impact on resilience and strength, which can reduce a person's ability to support themselves, their family, and the people they care for. Being self-aware of the effects of grief, stress, triggers and vulnerabilities is essential to avoid burnout and fatigue. Support can be as simple as a casual yarn with family or friends or as formal as accessing support services from ACCHOs.¹⁰

In summary

Aboriginal and Torres Strait Islander people, families and communities that have a serious illness that cannot be cured need easy access to culturally appropriate, quality, holistic family-centred palliative care.

Most people who require palliative care services can be managed in the community, so it is imperative that Aboriginal community-controlled health organisations receive appropriate funding, training and resources to provide this service to their communities.

For further information:

Annie Parks

annie.parks@qaihc.com.au

8. Aboriginal Health and Medical Research Council of NSW. (2023). *Journey to dreaming toolkit*. Aboriginal Health and Medical Research Council of NSW. <https://www.ahmrc.org.au/wp-content/uploads/2023/10/Final-Journey-to-dreaming-toolkit.pdf>

9. Palliative Care Australia. (2011). *Palliative care and Indigenous Australians: Position statement*. Palliative Care Australia. <https://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Palliative-care-and-Indigenous-Australians-position-statement-updated-16-8-11.pdf>

10. Australian Indigenous HealthInfoNet. (n.d.). *Palliative care and end-of-life care*. Edith Cowan University. <https://healthinonet.ecu.edu.au/learn/health-system/palliative-care/>

Recommendations

QAIHC calls on the Australian and Queensland governments to:

1. Support QAIHC to put forward palliative care for Aboriginal and Torres Strait Islander people as a topic of priority for the Queensland Aboriginal and Torres Strait Islander Health Partnership (QATSIHP), as a means to ensure stronger system investment in community-based, culturally informed, appropriate, and valued quality palliative care services are delivered. This needs to include a level of oversight of the broader palliative care investment to the system.
2. Support QAIHC to codesign culturally informed, appropriate, and valued community-based, quality palliative care services with ACCHOs.
3. Significantly increase investment to ACCHOs to enable ACCHO-led and delivered community based, culturally informed, appropriate, and valued quality palliative care services.
4. Support ACCHOs in developing and implementing local Aboriginal and Torres Strait Islander workforce and service development plans for ACCHO-led community-based, quality palliative care.
5. Support QAIHC and Member services to design culturally informed, appropriate and valued resources that amplify Aboriginal and Torres Strait Islander voices and self-determination, to empower families to access culturally informed, appropriate and valued quality palliative care service no matter where they are located.
6. Support QAIHC and Member services to develop culturally informed, appropriate and valued Aboriginal and Torres Strait Islander training and resources for general practitioners (GPs)s, nurses, Aboriginal and Torres Strait Islander Health Workers and Health Practitioners on provision of quality palliative care services.
7. Ensure specialist palliative care services enable and support Aboriginal and Torres Strait Islander people who choose to return to Country as their place of passing.