

Submission

Inquiry into Palliative Care in Western Australia

13 July 2020

The Aboriginal Health Council of Western Australia (AHCWA) is pleased to provide a submission to the Joint Select Committee's Inquiry into Palliative Care in Western Australia.

AHCWA is the peak body for 23 Aboriginal Community Controlled Health Services (ACCHS) providing primary health services across diverse metropolitan, regional, remote and very remote locations in Western Australia. AHCWA exists to support and act on behalf of its Member Services, actively representing and responding to their individual and collective needs. AHCWA's principal vision is for Aboriginal¹ people in Western Australia to enjoy the same level of health and wellbeing as all Western Australians.

AHCWA and its Member Services strongly support that all Western Australians should have timely access to comprehensive, culturally appropriate palliative care. In particular, Aboriginal people and their communities must have a clear understanding of what palliative care is, and must have the choice to receive palliative care services at home and on Country. AHCWA is firmly of the view that developing the capability of palliative care services across the state is a challenge for WA Health, and an opportunity for greater partnership with the ACCHS sector.

This submission will provide the Inquiry with some background to the ACCHS sector and its involvement in influencing the policy agenda around palliative care and end-of-life care. It will also expand on the issues raised in the Terms of Reference relating to: access to palliative care services across the state; the delivery of palliative care in regional and remote areas; and, progress on the implementation of recommendations of the *Joint Select Committee into End of Life Choices*.

Background

WA ACCHS are committed to ensuring that culturally appropriate health care is available to all Aboriginal people, their families, carers and communities across Western Australia. They are embedded in, and trusted by communities and are best placed to deliver palliative care services for Aboriginal people.

Common to all ACCHS is a commitment to delivering health and wellbeing services under a holistic Model of Care designed by Aboriginal people, for Aboriginal people. The Model of Care necessarily locates Aboriginal people within the context of eight determinants of health; family; community; culture; language; country; physical wellbeing; spiritual wellbeing; and, emotional wellbeing. Each of these

¹ Throughout this submission, AHCWA uses the term 'Aboriginal' to respectfully refer to all Aboriginal and Torres Strait Islander people across Western Australia.

elements is fundamental to the health and well-being of Aboriginal people, their families and communities and must be the foundation for any palliative care services for Aboriginal people in WA.

AHCWA has actively promoted the ACCHS Model of Care through engagement with key WA Government palliative care and end-of-life policy consultations in recent times. AHCWA staff appeared at the Joint Select Committee on End-of-Life Choices Inquiry in March 2018 to provide evidence on behalf of the sector, and provided a submission to the Ministerial Expert Panel's Discussion Paper on Voluntary Assisted Dying in May 2019. Throughout these engagements, AHCWA has strongly recommended the need for ACCHS to lead the end-of-life choices discussions with Aboriginal people, and to deliver culturally secure palliative care services within Aboriginal communities.

AHCWA acknowledges the release of *Implementation Plan One 2020-2022 (IP1)* for the *WA End-of-Life and Palliative Care Strategy 2018-2028* earlier this year. Due to the broad impact of the COVID-19 pandemic on the WA Health System, AHCWA has not yet had the opportunity to engage in this space, however, looks forward to any opportunities to engage meaningfully with WA Health on this work.

Information relevant to the Inquiry's Terms of Reference

Access to palliative care services across the state

AHCWA and its Member Services firmly believe and recommend that everyone should have the choice to receive palliative care services at home, wherever their home is located. Choice is significantly impacted by availability and access to services and, while AHCWA acknowledges that domiciliary palliative care is available in the Perth metropolitan area, this option is not available across the state. Access to comprehensive domiciliary palliative care services, including symptom control and end-of-life care, must be available to all people living in regional and remote areas.

True access to palliative care services for Aboriginal people also requires that those services are culturally appropriate. While there continues to be lack of access to comprehensive, culturally secure palliative care services in rural and remote areas, AHCWA welcomes the IP1's culturally sensitive approach for the future.

Palliative care service delivery in regional and remote areas

ACCHS staff are passionate about being able to provide quality palliative and end-of-life care to patients in their communities. Key enablers for this to occur include:

- Communication between palliative care specialists and tertiary hospitals, and regional and remote ACCHS;
- Recognition of the current skill and expertise of ACCHS clinics to deliver palliative care services in their local communities; and
- A genuine investment in the capacity and capability of the ACCHS sector to deliver palliative care services.

ACCHS must remain connected to their patients when they are in a tertiary hospital or under the care of a palliative care specialist, especially when discharge planning commences. Telehealth is an effective option for facilitating a collaborative discharge ensuring ACCHS are engaged early in the care of the patient. Often palliative Aboriginal people are discharged to small local hospitals in their

area, with no contact made with the local ACCHS as it is presumed that they do not have the capacity to manage palliative care. Issues also occur when ACCHS are engaged too late in the discharge planning process, at the last minute, and are required to support terminal care.

ACCHS currently support Aboriginal people with a life-limiting illness and their families in line with the holistic Model of Care. Palliative care interventions may involve: organising family meetings to plan palliative and end-of-life care; managing a roster of Aboriginal Health Worker staff who are trusted by the patient and their family to provide care; sourcing appropriate equipment and resources in a timely manner; and, engaging other services as required. As the care needs of a patient increase, many ACCHS are flexible and adaptable to the required changes in medical care and emotional support.

The capacity of ACCHS and clinics to deliver palliative care services varies across the state, however, all ACCHS have a variety of experience, expertise and diversifiable skills to provide culturally secure, primary health care to their communities. AHCWA strongly supports that the government commits to investing in capacity building across the ACCHS sector to deliver specialist community palliative and end-of-life care.

Progress on the implementation of recommendations of the *Joint Select Committee into End of Life Choices*

AHCWA offers general comments in relation to the recommendations detailed below:

Recommendations 8 and 13: Adequate funding for community and regional palliative care providers amid growing demand

- In addition to the issues previously noted regarding the need for capacity building for the provision of palliative care services, additional funding is also required to train Aboriginal Health Workers and other ACCHS staff to support their communities about palliative care.
- The need for capacity building extends to the preparation of resources for ACCHS to set-up or further develop palliative care services in regional and remote areas.

Recommendation 10 and 11: Appropriately defining palliative care, and providing comprehensive, accessible and practical information to educate professionals and communities about palliative care

- It is AHCWA's view that the WA community still does not have a clear and comprehensive understanding of palliative care. Too often, the perception is that palliative care is about providing medication for pain, and end-of-life care for 'cancer' rather than for other life-limiting conditions such as renal failure and other chronic diseases.
- There is a general lack of awareness that palliative care optimises the lives of patients (including their social, emotional and spiritual wellbeing), and that it is of value to all people with a life-limiting illness.
- There continues to be a lack of culturally appropriate resources for Aboriginal people to explain palliative care. Given the deep-seeded cultural perceptions of death and dying held by many Aboriginal people and their communities, it is very important that the benefits of engaging in palliative care in the early stages of a life-limiting illness are clearly defined.
- Resources and educational material must also be developed with culturally appropriate language and images to support community understanding of palliative care.

Recommendation 15 to 18: Ongoing professional development in palliative care for health professionals

- Many health professionals continue to demonstrate a lack of awareness of cultural considerations and protocols related to death and dying. Therefore, the importance of ACCHS in palliative care for Aboriginal people is reinforced, as some of these customary traditions may be sacred and not shared with people outside the community.
- Disappointingly, there are very few references to the need for culturally secure palliative care services in the *Joint Select Committee into End of Life Choices* report. AHCWA strongly recommends that all health professionals providing health care to Aboriginal people, whether it is palliative care or not, be required to undertake cultural safety training.

AHCWA notes that Recommendations 19-24 from the Joint Select Committee into End of Life Choices relate to Voluntary Assisted Dying and, while relevant, are outside the scope of palliative care. However, AHCWA acknowledges the proactive consultation conducted by WA Health with the ACCHS sector during the development of Voluntary Assisted Dying legislation in WA. Feedback from AHCWA and its Member Services was captured in the Ministerial Expert Panel on Voluntary Assisted Dying's final report, and AHCWA is continuing its engagement on this important issue through its representation on the Implementation Leadership Team.

Conclusion

AHCWA and its member services are very committed to ensuring that Aboriginal people across WA have access to high quality, culturally secure palliative care services wherever they choose to be. While the recommendations of the *Joint Select Committee into End of Life Choices* report provides some guidance for improvements in palliative care, further commitments to develop the ACCHS sector as partners in the delivery of palliative care in metropolitan, regional and remote areas is required.

Ultimately, a person's palliative care choices and journey belongs to the patient and their family; it should be at their pace and in their place, and should involve the early intervention of the local ACCHS in their community to ensure culturally secure care.