



Government of Western Australia
Department of Health

Aboriginal End-of-Life and Palliative Care Framework

A toolkit to support practices that promote the establishment of culturally safe end-of-life and palliative care services for Aboriginal people in WA.





Acknowledgement of Country and People

WA Health acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. It acknowledges the wisdom of Aboriginal Elders both past and present and pays respect to Aboriginal communities of today.

Use of the term Aboriginal

Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. Aboriginal and Torres Strait Islander may be referred to in the national context and Indigenous may be referred to in the international context. No disrespect is intended to our Torres Strait Islander colleagues and community.

Important disclaimer

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End-of-life and palliative care terms

The following terms, used in this document, are based on those in the *WA End-of-Life and Palliative Care Strategy 2018–2028*¹; terms used by the Australian Institute of Health and Wellbeing and the Australian Commonwealth Government. Further terms can be found in the glossary at the end of this document.

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end-of-life will be considered likely to die during the next 12 months.

End-of-life care

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers.

Palliative care

Palliative care is an approach that improves the quality of life of individuals, their families and carers facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family/carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.

Specialist palliative care

Specialist palliative care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. The role of the specialist palliative care services includes providing consultation services to support, advise, educate and mentor specialist and non-specialist teams to provide end-of-life and palliative care and/or to provide direct care to people with complex palliative care needs.

Terminal care

Terminal care is care of the dying person in the last days or hours of life.



Summary

The Aboriginal End-of-Life and Palliative Care Framework (the Framework) is designed to enhance knowledge and understanding of Aboriginal ways of working to empower health professionals and service providers across all health care settings to work more effectively with Aboriginal people to meet their holistic end-of-life and palliative care needs.

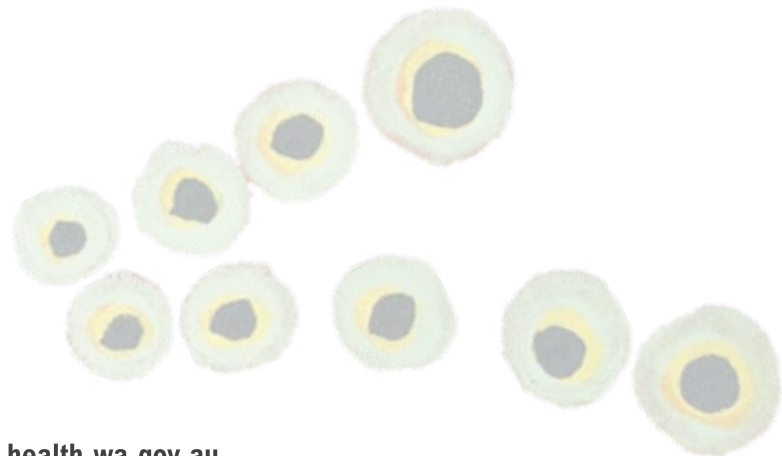
The Framework places the person at the centre of care and aligns with the *WA End-of-Life and Palliative Care Strategy 2018–2028*¹ (the Strategy), its *Implementation Plan One 2020–2022*² and the *Western Australian Paediatric Strategy for End-of-Life and Palliative Care 2021–2028*³ as well as the *WA Aboriginal Health and Wellbeing Framework 2015–2030*⁴. Combined, these documents outline the values and priorities for the improvement of statewide end-of-life and palliative care services in WA and the corresponding development of culturally responsive palliative care and end-of-life decision making for Aboriginal people, their families and carers.

The six key priorities areas identified in the Strategy¹ are applied in the Framework to facilitate a person-centred approach that meets the end-of-life and palliative care needs of Aboriginal people. Working with Aboriginal people, their families, carers and community to implement services and meet their needs must incorporate an understanding of and respect for Aboriginal ways of working.

Aboriginal traditions, values and cultural practises relating to palliative care and end-of-life transitions must be respected and included to ensure culturally safe and responsive end-of-life and palliative care.

The Framework also considers broader issues including the impact of the wider social and cultural determinants of health within a holistic and community-based context, that includes family, culture and historical legacy.

The Framework is a guide for health professionals and health care providers to facilitate a person-centered approach to end-of-life and palliative care for Aboriginal people. It prioritises working with Aboriginal people through Aboriginal ways of working so palliative care and end-of-life care decision making represent the needs of the person.



Introduction

Aboriginal health and wellbeing is not just the physical wellbeing of an individual but refers to the social, emotional and cultural wellbeing of the whole community in which each individual is able to achieve their full potential as a human being thereby bringing about the total wellbeing of their community. It is a whole of life view and includes the cyclical concept of life-death-life⁴.

The Aboriginal End-of-Life and Palliative Care Framework (the Framework) is designed to support health professionals and service providers across all health care settings to work effectively with Aboriginal people, by enhancing current knowledge and understanding of Aboriginal ways of working in relation to end-of-life and palliative care.

All Western Australians should have access to high-quality, person-centred, end-of-life and palliative care services that aim to improve the quality of life of people, their families, communities and carers facing life-limiting conditions through a holistic approach to care and management. The **WA End-of-Life and Palliative Care Strategy 2018–2028**¹ (the Strategy) and the corresponding **Implementation Plan One 2020–2022**², outline the values and priorities to improve statewide end-of-life and palliative care services in WA. The Strategy and its aligned document, the **WA Paediatric Strategy for end-of-life and palliative care 2021–2028**³, highlight the need to improve access to culturally respectful and appropriate palliative care for Aboriginal people, Aboriginal children and their families in their place of choice. The Western Australian health system continues to develop strategies to strengthen the delivery of person centered, culturally respectful and non-discriminatory⁶ end-of-life and palliative care services.

The Framework is guided by the key principles, strategic directions and priority areas contained in the **WA Aboriginal Health and Wellbeing Framework 2015–2030**⁴ and its **Implementation Guide for the WA Aboriginal Health and Wellbeing Framework 2015–2030**⁵. Specifically, this Framework aligns with the recommendation in the Implementation Guide Strategic Direction 1: Focus Area – Healthy Ageing Objective 5.1, that “Culturally appropriate aged care models, including palliative care and end-of-life decision making for individuals, their families and carers are developed and implemented”⁵.



Purpose of the Aboriginal End-of-Life and Palliative Care Framework

The Framework is designed to assist health service providers and administrators deliver culturally responsive practice to promote culturally safe end-of-life and palliative care services for Aboriginal people in WA. It should be noted that while voluntary assisted dying is now an end-of-life choice available to all eligible Western Australians, the Framework specifically focuses on other end-of-life choices that may be considered by Aboriginal people, such as advance care planning and palliative care support.

As such, the Framework is intended for use across all health care settings to guide continuity of care and a positive patient experience for Aboriginal people. Settings include primary care, the Aboriginal Community-Controlled Health Services (ACCHSs), hospitals, hospices, community providers including community palliative care services, specialist palliative care providers and Residential Aged Care Facilities. In line with the Implementation Guide⁶ it is intended to support better co-ordination, collaboration and continuity of care across government and non-government organisations and the ACCHS for a more person-centred approach.

While the focus is on cultural safety, the Framework considers connected issues and the impact of the wider social determinants of health within a holistic and community-based context, that includes awareness of family, culture and historical legacy.

The Framework is not a clinical document and should be used as a complementary resource, specific to the end-of-life and palliative care needs of Aboriginal people and their families and communities. It should be read and used in conjunction with existing guidelines and resources for the provision of culturally safe and appropriate care. See the **Resource List** for more in-depth information. These have been grouped into main themes and service settings for ease of navigation.

WA Health will support the implementation of the Framework by circulating it across the WA health system and to all relevant external stakeholders via the Department of Health website.

Providing high quality palliative includes:

- ▶ improving the overall quality of a person's life
- ▶ reducing suffering by early recognition and treatment of pain and other distressing symptoms
- ▶ affirming, improving quality of life and treating dying as a normal process
- ▶ caring for spiritual, psychological and cultural needs as well as physical needs
- ▶ offering a support system to help the family, carers and community cope during their relative's illness and in their own bereavement
- ▶ using a team approach to address the needs of individuals and their families, including bereavement counselling, if indicated.



Ancient land, ancient people – Aboriginal people themselves are the cultural experts in the room

Many diverse groups of Aboriginal peoples, with different languages, cultures, beliefs and practices, have called Australia home for at least 60,000 years^{6,7}. For Aboriginal people, “Country” encompasses an interdependent relationship between an individual and their ancestral lands and seas. Cultural practices and beliefs around health and wellbeing, the causes of poor health and end-of-life and dying may not be consistent with Western ideology^{6,7,8}. Health and wellbeing for Aboriginal people is linked to spirituality, connection with land and the harmony of interrelating factors. When people talk about ‘Country’ it is spoken of like a person: *we speak to Country, we sing to Country, we worry about Country and we long for Country*⁹.

Land is of great significance to Aboriginal peoples – but the connection to Country can be a difficult concept for non-Aboriginal people to grasp. The living environment goes beyond physical elements and is fundamental to our identity and wellbeing.

“The land is the mother and we are of the land; we do not own the land rather the land owns us. The land is our food, our culture, our spirit and our identity”

Dennis Foley, a Gai-mariagal and Wiradjuri man, and Fulbright scholar¹⁰.

Rather than owning the land, there is a relationship between Aboriginal people and the land and seas based on respect. While the land sustains and provides for the people, they in turn manage and sustain the land through culture and ceremony. The land is a link between all aspects of Aboriginal people’s existence – spirituality, culture, language, family, law and identity.

Fig 1. AIATSIS map showing the language or nation groups of the ATSI people of Australia



Burden of disease

Aboriginal people represent only 3.6 per cent of the total WA population, and yet have some of the greatest health needs and challenges of any groups in the State¹¹. In WA, the burden of disease for Aboriginal people is more than double that of non-Aboriginal people¹¹. Aboriginal people in WA die at younger ages than non-Aboriginal Western Australians. Life expectancy is 13.4 years lower for Aboriginal men and 13.1 years lower for Aboriginal woman compared to non-Aboriginal West Australians^{12,26}. The death rate for Aboriginal children in WA for 0–4-year-olds remains higher than for non-Aboriginal children¹³.

Aboriginal people have a higher risk of developing chronic disease, of greater complexity and at a younger age, in some cases up to 20 years earlier, than non-Aboriginal Australians¹¹. This contributes to more Aboriginal people experiencing a life limiting illness that requires earlier access to end-of-life and palliative care services. Aboriginal children too are impacted by their parents' end-of-life and palliative care needs. The rate of palliative care related hospitalisations in WA is more than twice as high for Aboriginal people compared to other Western Australians and is increasing (from 2.55 times in 2015 to 2.71 in 2019)¹³.

Multiple co-morbidities can complicate both understanding and the care pathway, along with culture, communication styles, family structures and beliefs that are not always known or understood by other Australians. <https://pepaeducation.com/support-and-education/cultural-considerations-providing-end-of-life-care-for-aboriginal-peoples-and-torres-strait-islander-peoples/>.

Figure 2 shows the complex interdependencies of the social determinants that impact on people's health and wellbeing¹⁴.

The Aboriginal Health and Wellbeing Framework⁴ points to the importance of culture as a determinant of the health and wellbeing of Aboriginal people. The cultural determinants of health are strength-based and include the positive impact of self-determination and resilience, individual and collective rights, connection to country and community, reclamation of language and cultural practice, and freedom from discrimination.

The Aboriginal Health and Wellbeing Framework⁴ includes definitions of health and the importance of strong partnerships between services and community to encourage new ways of working.



Fig 2. Social determinants of health

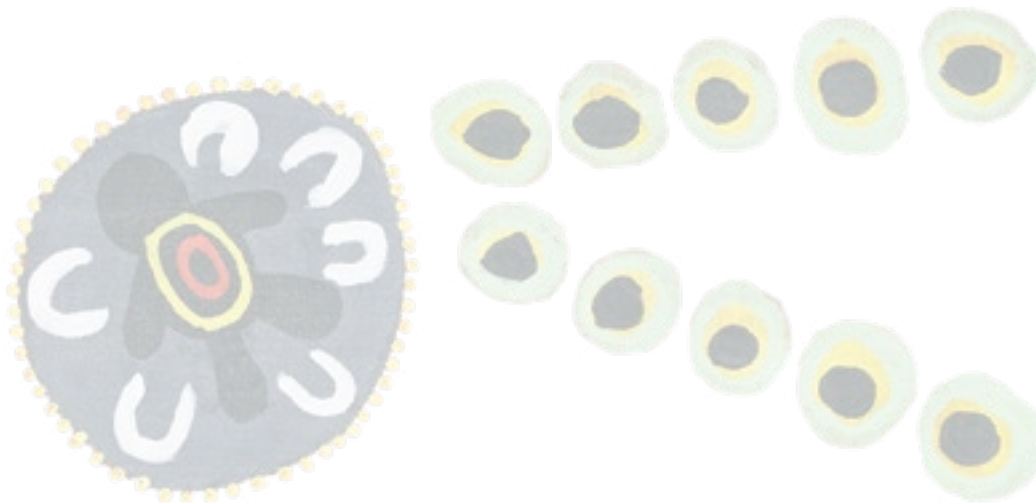


Working with Aboriginal people and Aboriginal ways of working

There is no one size fits all approach to working with Aboriginal people, their families, carers and community. Best practice is to engage with the person in a respectful and considerate way to find out their cultural needs and obligations to support appropriate care planning^{7,15,16}.

The Aboriginal Health and Wellbeing Implementation Guide⁵ highlights the need for a flexible, rather than a prescriptive, approach to implementing services for Aboriginal people to achieve the best results.

- ▶ Everyone is different and has different beliefs and needs.
- ▶ At the first point of contact all people should be asked “Do you identify as Aboriginal or Torres Strait Islander origin or both?” Be prepared to explain why you are asking this question.
- ▶ Be up front with the person and family about what your role and your scope of practice are. Do not make promises that you cannot fulfil.
- ▶ Ask the person, care giver/family member who is the most appropriate person to discuss the person’s care with; who is the person responsible or their next of kin; is there an alternative if they are not available.
- ▶ Ask the person if they have any family or friends working at the present facility as the Aboriginal community is small and they may not want to share their business.
- ▶ You must obtain consent from the person before contacting the Aboriginal Health Liaison Service. Please consider and respect that not all Aboriginal people will want to be seen by an Aboriginal Health Liaison Officer (AHLO).

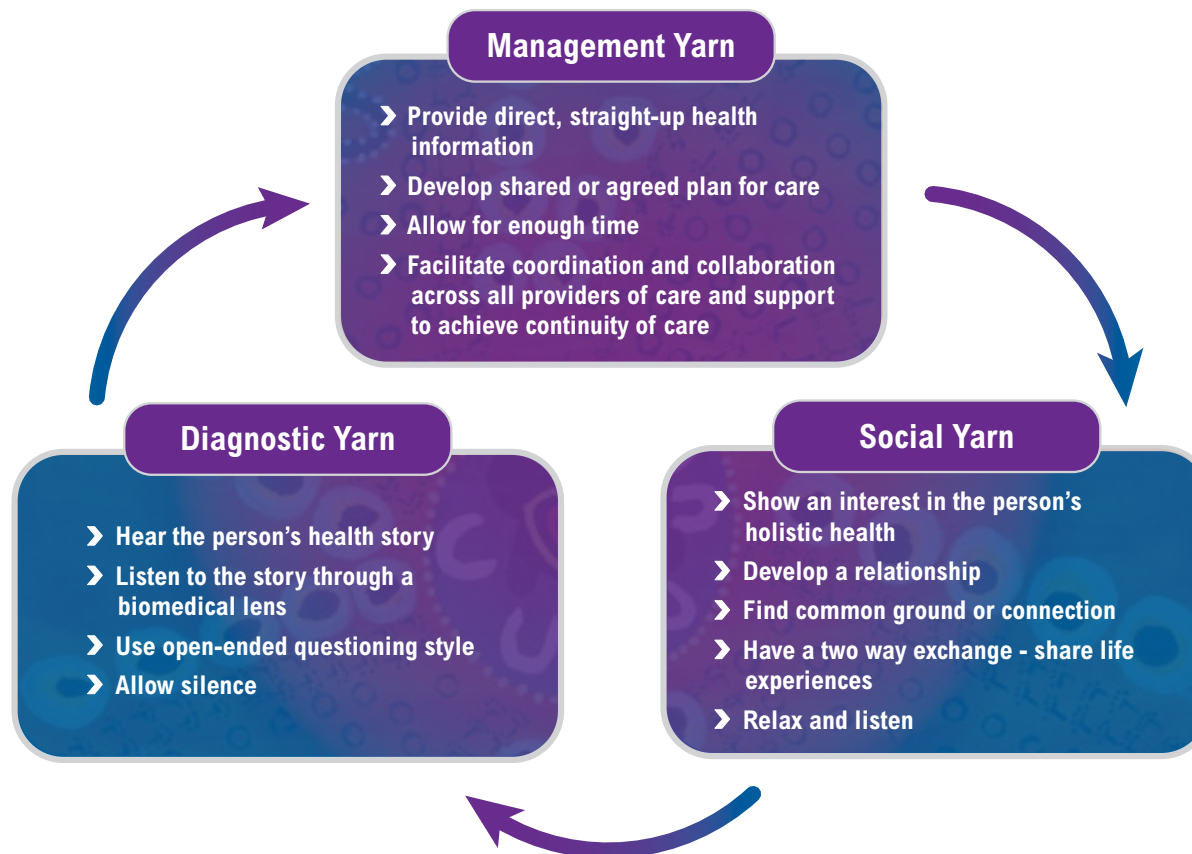


Clinical Yarning

Aboriginal people often speak in a narrative/conversational style, using stories and will talk around a topic to illustrate a point. Direct communication can be confronting for some people and may discourage the person and community from participating in a discussion of their healthcare options.

Healthcare professionals may engage better with Aboriginal people by incorporating 'yarning' into their interactions. 'Clinical Yarning' includes the diagnostic, the management and the social yarn¹⁷ as described in Figure 3. Combined they provide a holistic approach to communicating with Aboriginal people.

Fig 3. The Clinical Yarning Cycle



Communication

Most Aboriginal communities have their own language and dialect, especially remote communities. The Aboriginal language spoken within the community is unique to their sense of identity and connects the people to their stories and dreaming. English may be the third or fourth language spoken in some communities. A culturally safe approach to language difference is needed and Aboriginal language interpreters should be engaged when appropriate.

The first few minutes of your initial interaction with the person can set the tone for the remainder of your relationship. Recognising the impact of the past and Aboriginal peoples' diverse and rich cultural history can help build trust and confidence. It is important that health professionals communicate on a level which both find understandable and comfortable. Feeling safe and secure is fundamental to the delivery of culturally responsive health care.

- ▶ Open, honest and sensitive communication from first contact will help build trust and rapport with the individual, family and community.
- ▶ It is important to ensure that the person, carer and family understands their care options by:
 - › using simple terms rather than complex medical terminology
 - › checking in often to confirm their understanding
 - › using interpreting services where needed. English may be a second or third language for Aboriginal people, leading to possible difficulties in communicating information^{6,8,16}
 - › Allowing for time for the person and carers to process information. You may need multiple family meetings to address questions and issues.
- ▶ Offering the services of an Aboriginal health worker if available; the person has the option to refuse.
- ▶ Accessing a person in the family, though it is important to recognise that this may be a last resort to assist in communication.
- ▶ Be conscious of non-verbal communication such as hand signs, facial expressions and body language.
- ▶ Aboriginal people may communicate in many ways.
 - › Responses can range from quiet and reserved to assertive.
 - › Communication may be through a family member or carer.
 - › Communication may be through body or sign language or motions.
 - › The person might not verbalise pain or report issues even when asked¹⁸.



Active listening

- ▶ Do not assume anything. Do not judge.
- ▶ Ask for clarification if you are unsure what the person means.
- ▶ Be patient, allow for silence.
- ▶ Pay attention to not only the person's words but also their body language or sign language.
- ▶ Provide verbal and non-verbal feedback to show attentiveness – e.g. nod, smile.
- ▶ Summarise the person's responses and repeat back to them.

Engaging with Aboriginal people

The ability to effectively engage with Aboriginal people especially if English is not their first language is integral to best practice and safe quality care. Many Aboriginal people, especially those from remote areas, can find hospitals frightening and foreign. It is the extra effort from staff that builds rapport and helps alleviate anxiety. Effective engagement ensures a person is aware of what is happening to them and encourages participation in decision-making about their health and treatment options.

Men's and Women's Business and the protocols surrounding these must be considered and respected within the provision of care^{6,7}. They may also cause barriers for the person to talk openly and this must be taken into account^{6,15}. Aboriginal people may have a general feeling of distrust of non-Aboriginal health staff⁶. This may be due to past experiences, historical factors or possibly feelings of being judged or being treated unfairly in unfamiliar environments, such as mainstream health services⁶. There may be further challenges where children or young people are involved.

Developing effective relationships with local Aboriginal communities increases awareness and understanding of local cultural beliefs and practices.

Challenges that may be experienced

Palliative and end-of-life care is commonly perceived as solely care of the dying and care after death, however it has an important role in advancing illness to improve quality of life and wellbeing.

Contemporary models of palliative and end-of-life care in Australia are dominated by western traditions and the biomedical paradigm. Aboriginal traditions, values and cultural practises relating to palliative care and end-of-life transition must be included to ensure culturally safe end-of-life and palliative care. There are some challenges in providing culturally appropriate palliative and end-of-life care.



- ▶ Aboriginal people have strong family and community connections and will often consult their family members to ensure that everyone is aware of treatment options and understands how different care plan choices may impact on the outcome for the person. Staff may be required to facilitate an all-of-family conference, including those ‘on country’, to support the individual and coordinate their care plan.
- ▶ It may be necessary to identify a ‘go to’ person; someone you see is connecting with all family when decisions and or questions are asked. Take the cues from person, carer and family.
- ▶ Some Aboriginal people may have a different understanding about diagnosis and treatment. This may be due to spiritual and cultural beliefs which may conflict with western medicine ideology. It is important to unpack this and talk with the person, family and community about their choices. Whilst respecting the wishes of family, it is important to acknowledge the person as the ultimate decision maker in matters related to their care.
- ▶ Past experiences with health services may impact on the person and family accessing treatment. In some cases, the health service may be judged for perceived past treatment of the person concerned and/or others. Word of mouth is a powerful influence on opinions and actions, so it may be hard to overcome previous negative experiences. Ensuring staff are culturally respectful and aware of peoples’ beliefs will assist in building trust and encouraging better communication between an individual and staff.
- ▶ Aboriginal people may be reluctant to engage in conversations about end-of-life and dying, both for themselves and their families. This can make it difficult to discuss serious medical diagnoses, treatments and complications. However, the approach must include the ‘hard to have’ conversation on “what are your options and choices about end-of-life care and dying”.
- ▶ Where the end-of-life and palliative care issues relate to the experiences of a child, their family and community, the challenges are greater for all concerned.

Following the death of a person

There are cultural expectations that families need to adhere to following death. Duties are performed out of love and cultural obligation and can include supporting immediate families, helping with transport, housing and meals. It is important to ensure that all have the opportunity to pay their respects, especially if they were unable to do so before the person passed away.

Conversations regarding end-of-life and death must be culturally sensitive.

- ▶ Some Aboriginal people find it inappropriate to say or write the name of a person who has recently died. Use of images or voice recordings of the deceased person may also be considered disrespectful^{18,20}.
- ▶ Ask the deceased person’s family about appropriate words for staff to use, especially when referring to the person who has died. For Aboriginal people using the word “pass or passed away” are the preferred terms.



- ▶ People may have family or friends working at the health care site; ensure cultural protocols are adhered to and be sensitive when informing Aboriginal staff of a death or impending death.
- ▶ Contacting the next of kin following the death is not always correct practice for Aboriginal people^{8,15}. It may also be culturally inappropriate for a non-Indigenous health staff member to contact and inform the next of kin of a person's passing. It is important to determine the correct protocols and people to be informed following the person's passing. These should be determined prior to the death.
- ▶ If you are unsure of cultural protocols the Aboriginal Health Liaison Service may be able to provide advice (consider relationships as above).
- ▶ Grief of the whole community and not just the immediate family is important to Aboriginal people. Provide time for family to come and pay respects (distance to travel and size of gatherings might need to be considered).
- ▶ Social work support can be sought to assist with funeral processes if required.

Sorry Business following a death

Many Aboriginal people refer to bereavement as 'Sorry Business'. This is an important period of mourning; family time is very significant culturally.

It involves obligations to attend funerals, participate in cultural events and traditional ceremonies and take responsibility to support family members in a multitude of ways such as; help with food, travel, accommodation and finances.

Mourning may last for days, weeks and even months. This is sometimes known as 'Sorry Time'. Sometimes in regional areas, the entire community will be closed during Sorry Time.

Be conscious of local protocols based on regional differences. Examples of how Aboriginal people show grief in traditional ceremonies may include:

- ▶ expressions of grief can take the form of wailing by those gathered
- ▶ taking part in 'smoking ceremonies' to assist safe travelling into dreamtime
- ▶ some relatives may cut off their hair.



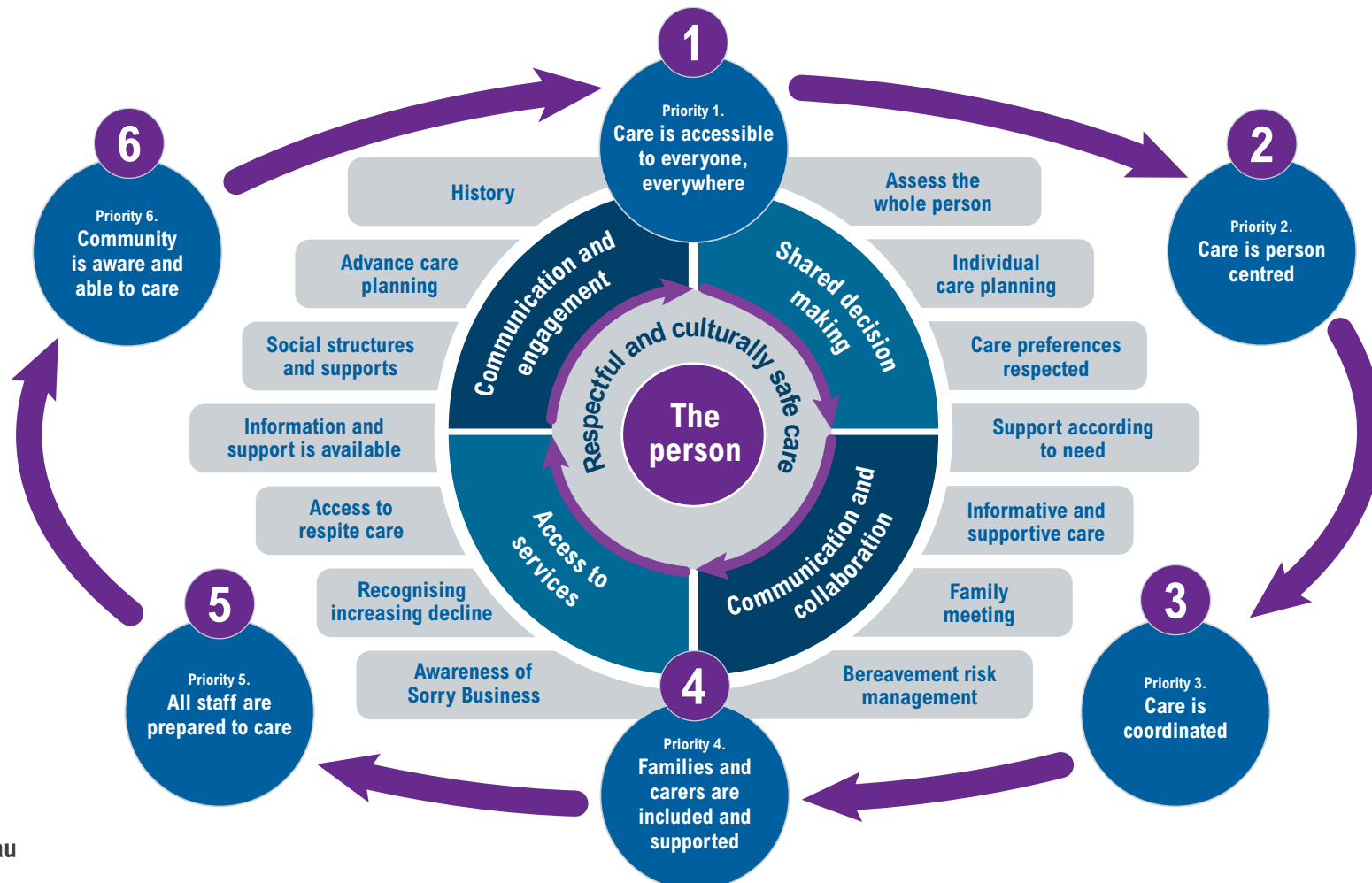
Things to think about when applying the palliative care priorities to Aboriginal people

The Framework applies the six priority areas identified in the Strategy to guide and inspire people to work together in a person-centred way to develop local services that meet the end-of-life and palliative care needs of Aboriginal people.

A key message to convey to the person, their family and community is about the value of palliative care in improving symptom management and quality of life¹⁵.

'If you get healthcare right for Aboriginal people you get it right for everyone'.

Fig 4. Holistic palliative care approach for Aboriginal people





Priority One | Care is accessible to everyone, everywhere

Having access to good quality end-of-life and palliative care regardless of who and where I am, or how I live my life.

A person has the right to choose how they spend their last days. Their choices will have a significant impact on the outcomes for themselves, their family and community and also the care they will receive^{6,21}. A key building block to realising Priority One of the Strategy is improving access to end-of-life and palliative care for Aboriginal people.

Many Aboriginal people express a preference to remain on, or return to, Country to be close to family and community when receiving care in the final stages of life^{6,15,16,19,20}. This request should be honored with the clear understanding that the level of care may be significantly different to that received within the health service. Returning to Country is not without its challenges. Access to specialist end-of-life and palliative care as required is not always readily available in regional and remote communities, however the need to be with family^{6,15,16,19,20}, community and on Country may be more important to the person than the treatment of their disease^{6,21}. On Country does not necessarily mean rural and remote, many people live in metropolitan or regional areas. Information and support should be provided to families and carers, to ensure quality care and the comfort of the person in their place of care or preferred place of death. Communication is key – ensure the individual, carers and family are involved in care and discharge planning and understand that their wish to return to country or leave the care facility may impact on their health outcome.

Tips

- ▶ Cultural needs may outweigh medical needs.
- ▶ Consider all travel and health requirements for the person to return to country. Investigate alternative ways for a final journey to be undertaken if they are unable get clearance to travel. This might require thinking out of the box and option to consider are below.
 - Find living arrangements with family close to treatment
 - Make arrangements for family and people from the community to assist with end-of-life protocols
 - If the person is allowed to return to country but can't fly, perhaps family could drive to the hospital to collect them.
 - Bring Country into the care setting in ways that are significant to the person, for example, food, plants or soil.
- ▶ It is important to consider the capacity and level of care that the family can provide and realise that medical perspectives regarding their needs may not align with those of the person and their family. The cultural needs may outweigh the medical ones.



Tips continued

- ▶ Be honest; tell them that it is possible they may not have the same care available on returning to country and they might pass away sooner. However, returning to Country may still be their priority and might have a positive effect.
- ▶ Plan proactively and flexibly for continuity of care on discharge. Provide the person with the physical resources for their care which include input from local medical and non-medical community services i.e. beds, support services, local contacts, medications and travel arrangements.
- ▶ Local contacts can facilitate appropriate and effective care and support for the person, their carer and family in the person's location of choice. They include Aboriginal health workers, Aboriginal Community Controlled Health Services (ACCHS), Aboriginal Health Services, consultative palliative care services such as the Metropolitan Palliative Care Consultancy Service (MPaCCS), Regional Palliative Care Services, residential aged care facilities and primary care. A Compassionate Communities (<https://palliativecare.wa.asn.au/compassionate-communities/>) project or network could assist if there is one nearby.
- ▶ Include the above in the discharge and care plans and make sure the person, their carer and family understand what they have committed to and have a chance to reflect on and confirm this.
- ▶ Video conferencing can be used to support care everywhere, for everyone.

Goals of Patient Care discussions are conversations, led by the clinicians, that aim to arrive at agreement between the healthcare team, the person and their family about what medically appropriate and realistic goals of patient care would be. For example, would the person want to be sent to hospital if they developed pneumonia again? If the person's decision was 'no' then the team would develop a plan to support care preferences.





Priority Two | Care is person-centered

I am seen as an individual and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

An Aboriginal person's beliefs around their health and holistic wellbeing and the causes of poor health may not always be consistent with Western medical explanations^{3, 6}. Care of the person at end-of-life may involve input from traditional spiritual healers as well as mainstream health service providers⁵, each individual will have differing needs. The needs of Aboriginal people living in urban, rural and remote locations will also differ and must be considered in care planning^{4, 5}.

Discussion around diagnosis, prognosis and future management of the person's medical condition or their disease can be effectively supported by local health service providers within the context of family and community. Advance care planning and the Goals of Patient Care process, if used sensitively and flexibly, can help to ensure care planning reflects the person's preferences, values and cultural beliefs. It is important that these are communicated formally and shared with those providing care. Priority Six contains further detail.

Aboriginal people and their families are vulnerable during the final stages of life, so sensitivity is required. Healthcare staff must be aware that their own cultural beliefs and experiences may impact on their acceptance and understanding of the person's belief system. Working within the person's cultural paradigms will provide better culturally safe care and support for the person and their family in the end stages of life¹.

Tips

- ▶ Effective communication of diagnosis, prognosis and management will facilitate more active engagement by the person in their care at home.
- ▶ Some Aboriginal people believe that gathering together helps prepare the person for their passage to the afterlife. Gathering may also benefit the people left behind by planning for and allowing quality time to prepare for the loss and grief that will follow when the person passes.
- ▶ Be open about making any changes to the care plan or the person's Goals of Patient Care to accommodate their wishes. Include key people as determined by the individual and family and cultural protocols.
- ▶ When it is known to a family or community that there is an expected death of an Aboriginal person, large gatherings may take place to support and show respect for the family. Plan for and allow a culturally safe space for people to gather.
- ▶ Encourage and allow key family members to be involved in the care of the person at all stages of life.





Priority Three | Care is coordinated

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

Coordination is essential to the management of care and treatment in the person's place of choice. Working in partnership with the person's usual health care team, local health and community services and family members enables the person to receive quality care wherever they choose. In some locations, ACCHS and Aboriginal Health Services may be available to support individuals and families.

Development of care plans requires knowledge and inclusion of the range of resources and services for the individual and family support. Discharge planning must include:

- ▶ priority given by acute health service providers for early planning and liaison including verbal clinical handover with the person's local health service
- ▶ recognition that coordinated care is not just health based. Addressing social determinants through social service providers such as Integrated Team Care, transport, equipment is also essential
- ▶ multi-disciplinary support taking a holistic approach inclusive of traditional healers, pastoral care and traditional medicine
- ▶ recognition of the person's belief system, values and what's important to them.

Tips

- ▶ Remember people transferred from rural to metropolitan areas and vice versa might need additional support.
- ▶ Establishing relationships with Aboriginal staff (in clinical and non-clinical roles) within the health care facility may assist with learning local cultural practices that may impact on care and treatment^{6,7}.
- ▶ Establish links with consultative palliative care providers in the appropriate setting, for example, WA Paediatric Palliative Care Service, Metropolitan Palliative Care Consultancy Service (MPaCCS) and Regional Palliative Care Services when specialist palliative care input is required.





Priority Four | Families and carers are supported

Those close to me and or caring for me are supported and involved in my care. The contributions made by my family/carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

Support is essential for a person with a life limiting illness, particularly in the final stage of life. For Aboriginal people the family and kinship system can provide a wealth of support and is extremely important⁶. Certain family members hold specific roles and responsibilities and will be able to assist with delivery of care at this time¹⁶. Understanding and supporting these cultural roles and responsibilities will help ensure culturally appropriate care is received by the person⁶.

Family and carers must be:

- ▶ involved in planning and decision making early in the journey and as much as the person requests
- ▶ supported and have their needs met throughout the journey of palliative and end-of-life care including having an awareness of what to expect regarding the end-of-life changes particularly as death approaches
- ▶ involved in planning to be present as end-of-life approaches
- ▶ supported and able to undertake their roles and responsibilities and be involved in the person's care if that is the person's wish
- ▶ supported after the death to undertake cultural practices
- ▶ supported in their loss, grief and bereavement
- ▶ practical support with access to superannuation, native title trusts, wills, Centrelink, funeral planning as necessary.

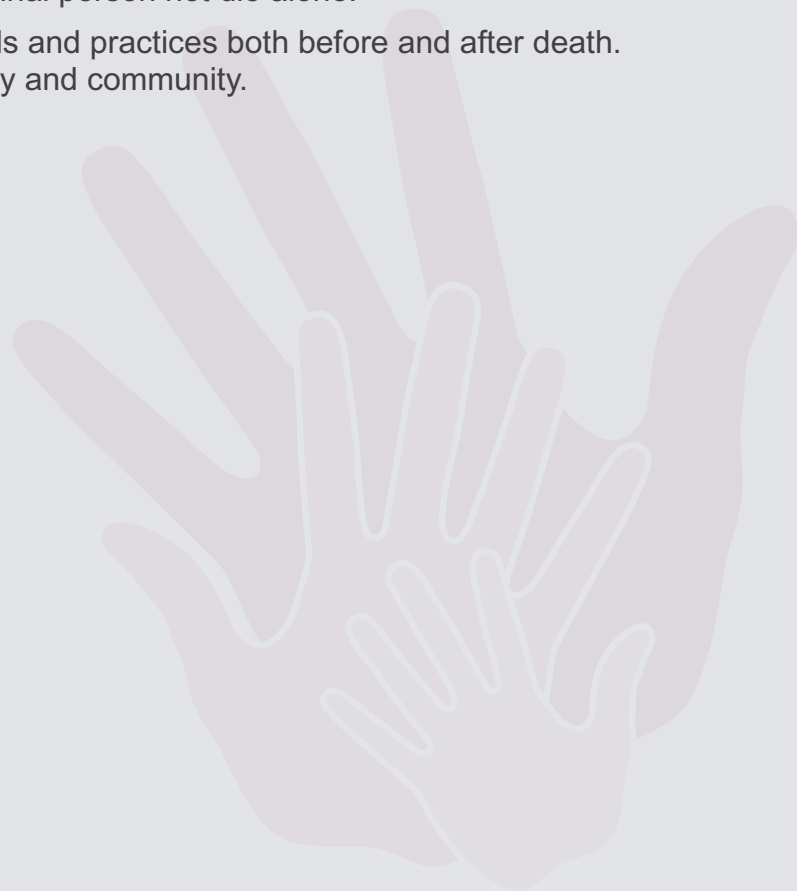
The time of passing is very emotional for family and friends of the deceased. Continued support, sensitivity, understanding and respect for cultural protocols and practices is required⁶. When a family member dies, Aboriginal people spend "Sorry Time" with their family members and grieve with them. Sorry Time is very important Aboriginal business and is very individual¹⁹.

When the person nearing death is an in-patient, pre-emptive planning to enable visiting must occur in an as streamlined a way as possible. Coordinate with the family spokesperson and/or the AHLO/AHW for the best way to accommodate all who wish to visit the person at the end-of-life. Bear in mind that there may be many wishing to do so and allow for space. If a member of a community, particularly an Elder, has died or their health is deteriorating, many community members will gather to respect and honour the person. Flexible visiting guidelines should be considered for people who are not 'family' but still have an obligation to visit and pay last respects.



Tips

- ▶ Early and respectful identification of the correct person to contact in the event of the person passing is essential. This person may not necessarily be designated 'next of kin'.
- ▶ Consider providing a culturally safe space such as a larger and more private room for the person, as large numbers of visitors should be anticipated.
- ▶ Flexible visiting hours for Aboriginal people should be considered as family members may be travelling long distances.
- ▶ Family members may request to stay with the person overnight. This is important to facilitate as often the family member is the person's only connection to country and it is very important that an Aboriginal person not die alone.
- ▶ Care pathways must have flexibility to accommodate Aboriginal cultural protocols and practices both before and after death. Offer information in multiple formats to meet the needs of the person, their family and community.





Priority Five | All staff are prepared to care

Wherever and whenever I am cared for, all staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care, before, during and after my death.

End-of-life care is everyone's business¹. Care is provided to those with a life limiting illness across health, community and aged care sectors by both generalist clinicians and specialist palliative care service providers.

In order to deliver end-of-life and palliative care that is responsive to an Aboriginal person's cultural needs, service providers must have good understanding of the cultural knowledge and skills that impact on practice³. Ensure all staff have access to Aboriginal cultural learning resources and have completed appropriate training when mandated.

It is equally important that staff who have expertise in providing culturally respectful and responsive services to Aboriginal people, such as AHLOs, AHWs and Aboriginal language interpreters, have an understanding of end-of-life and palliative care including advance care planning, clinical care and bereavement support. Services should include the provision of end-of-life and palliative care education and training for Aboriginal Health Workers, Aboriginal Health Liaison Officers and Aboriginal Language Interpreters.

More information about the education and training resources can be found in the ***Resource list***.





Priority Six | The community is aware and able to care

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close by me.

Talking about end-of-life planning can be a difficult and sensitive topic for anyone and particularly for Aboriginal people, this may be due to their cultural beliefs regarding death^{16,19, 20, 22}. Reasons include the perceived taboo and discomfort around talking about death, communication barriers, disjointed care with no single health professional taking responsibility for initiating the discussions, uncertainty in prognosis, lack of availability of family (often limited by distance, time and priority) and scarcity of Aboriginal health workers.

Advance care planning involves a person having conversations about their future care preferences. Conversations may have taken place with family but not relayed to healthcare practitioners and vice versa. The person must be supported to identify and document their future wishes for end-of-life care that will fit in with their individual social, emotional, and cultural needs and values. This is in preparation for a time when people are no longer able to make or communicate their decisions^{22,20}. Advance care planning conversations can provide clarification around important issues such as where a person would prefer to receive their health care, the types of treatment they do or don't want, and their preferred place for end-of-life care.

Ideally advance care planning should begin when someone is diagnosed with a life-limiting illness or before major acute health events. For many Aboriginal people involvement of the family in these discussions is very important. The person should be given enough information about options for their care to empower them to make decisions for themselves. At all times the person's values and choices should guide clinical decision making, with the family's wishes respected where appropriate¹⁹.

Even though many are of the view that talking about end-of-life care is not well-liked by Aboriginal people, Sinclair and colleagues demonstrated an acceptance of advance care planning discussions in their qualitative study of Aboriginal people in the Great Southern region of Western Australia²⁷. The study participants raised family conflict as one of their concerns at end-of-life and identified that engaging in advance care planning could help to reduce family disputes. The authors called for an increased role for the family, use of Aboriginal health workers, and a whole-of-community approach in implementing advance care planning.

Early sensitive and culturally safe discussion around advance care planning and the benefits of documenting future care preferences, will increase community knowledge of palliative and end-of-life care and may encourage advance care planning uptake by people in Aboriginal communities.

A range of documents can be completed through the advance care planning process, depending on the person's circumstances and choices.



An Advance Care Plan (ACP) is a document that captures a person's values and preferences in relation to the future care they might or might not want and the place where it happens. An ACP is not a formal legal document but can be used to help someone clarify and communicate their wishes for their future health care to their family and healthcare staff. It can indicate the person's treatment and care choices and the extent they wish treatment to continue and where. Aboriginal people transferred from rural and remote communities to the metropolitan area for medical investigation will often be fearful that they will not be allowed to return to country. An ACP can be made if the person has decision-making capacity or even if they do not.

- ▶ Goals of Patient Care are clinician led conversations that support shared decision-making about care during clinical deterioration and to discuss the implications of treatment decisions. Through these conversations medically appropriate and realistic goals of patient care are established and documented between the person, their family and the medical staff.
- ▶ An Advance Health Directive (AHD)* is a formal legal document that can only be completed by an adult who has the mental capacity to make decisions now about their future health care wishes when they can no longer make decisions. There are rules about how an AHD must be presented and how it must be signed and witnessed.
- ▶ A person can appoint one or two people they trust to make healthcare decisions on their behalf in the future, if they are no longer able to make decisions themselves, by making an Enduring Power of Guardianship (EPG). The Office of the Public Advocate is responsible for EPGs. An EPG is a legal document and there are rules about appointing an EPG and the forms to use.

Tips

- ▶ Initiate advance care planning conversations early when possible.
- ▶ Create care pathways that allow enough time and resources to engage people and their families in advance care planning. The person and their family may need some time to interpret the health care information, discuss it, and come to a common understanding and acceptance of the person's wishes.
- ▶ Engage with the person and their family/community to find out about the cultural beliefs and needs that will impact on effective advance care planning conversations.
- ▶ Encourage people to record their wishes in a way that will be recognised and followed by health care practitioners when they are no longer able to make decisions, such as an AHD because it is a legal document. These conversations should be handled in a respectful way that recognises the person and their family's underlying values and belief structure. Use the information from the 'working with¹ Aboriginal people and Aboriginal ways of working' section to prevent the formal, structured approach involved in making an AHD, from putting the person off the process¹⁵. Use the information sensitively to help people to understand their options.

* In some states of Australia an AHD is known as an Advance Care Directive



Tips continued

- ▶ Train Aboriginal health workers in advance care planning, ACPs, AHDs and Goals of Patient Care.
- ▶ Involve AHLOs/AHW, family and significant community members in advance care planning whilst still ensuring that any decisions are autonomous and not overridden by a collectivist approach.
- ▶ Use existing resources in the initiation of advance care planning conversations with Aboriginal people. See the **Resource List** for more information.
- ▶ Completed documents should be stored so they are easily accessible. Ideally copies should be shared with family/community members, and all teams and organisations involved in treating the person. They can be uploaded to MyHealthRecord where they will be available (see below to access instructions).
- ▶ Additional information and forms.
 - ACP and AHD forms and information can be obtained from the WA Department of Health. Phone 9222 2300. Email acp@health.wa.gov.au. Visit the website https://www.health.wa.gov.au/Articles/A_E/Advance-care-planning.
 - WA Health has endorsed the National Framework for Advance Care Planning Documents. It can be found at this link www.health.gov.au/resources/publications/national-framework-for-advance-care-planning-documents.
 - Instructions for uploading an AHD to the person's My Health Record. Phone: 1800 723 471. Visit the website <https://www.myhealthrecord.gov.au/help/advance-care-plan-and-goals-of-care> or www.myhealthrecord.gov.au. The AHD should be stored under the TAB -Advance Care Planning documents.
 - EPG forms and information can be obtained from the Office of the Public Advocate. Phone: 1300 858 455 or 9278 7300. Email: opa@justice.wa.gov.au. Visit the website <https://www.publicadvocate.wa.gov.au/>.
 - <https://www2.health.wa.gov.au/~media/Corp/Documents/Health-for/End-of-Life/End-of-Life-Care-for-People-with-Dementia-Framework.pdf>.



The following resources may be of use to service providers in the planning and provision of culturally respectful and appropriate and palliative care for Aboriginal people.

General

MAPPA is a free-to-use online mapping tool that works to help people and communities to better-access health services as close as possible to family, home and country. It is being built through strong consultation with the health sector and the wider community and is for all people to use: <https://mappa.com.au>

Language – Aboriginal Interpreting WA: <https://www.aiwaac.org.au>

End-of-life and palliative care for Aboriginal people

Sad News, Sorry Business: Guidelines for Caring for Aboriginal and Torres Strait Islander people through death and dying. Queensland Health: https://www.health.qld.gov.au/__data/assets/pdf_file/0023/151736/sorry_business.pdf

Palliative care knowledge network. Aboriginal and Torres Strait Islander Care Hub. Care Search: <https://www.caresearch.com.au/caresearch/tabid/3855/Default.aspx>

Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer. Australian Government, Cancer Australia: <https://www.canceraustralia.gov.au/sites/default/files/publications/optimal-care-pathway-aboriginal-and-torres-strait-islander-people-cancer/pdf/optimal-care-pathway-for-aboriginal-and-torres-strait-islander-people-with-cancer.pdf>

Cultural Considerations, Providing end of life care for Aboriginal peoples and Torres Strait Islander peoples. Program of Experience in the Palliative Approach (PEPA):

<https://pepaeducation.com/wp-content/uploads/2019/07/2651-Pepa-Indigenous-FlipChart-F4-LR.pdf>

<https://pepaeducation.com/support-and-education/cultural-considerations-providing-end-of-life-care-for-aboriginal-peoples-and-torres-strait-islander-peoples/>

Going Home to Dreamtime – a brochure about Palliative Care Services in the South West:

https://pepaeducation.com/wp-content/uploads/2021/03/S283_WAoriginalResource_A4Flyer_LR-1.pdf

Providing culturally appropriate palliative care to Aboriginal and Torres Strait Islander peoples – Resource. Mungabareena Aboriginal Corporation, Wodonga institute of TAFE and Mercy Health Service Albury (Palliative Care):

<https://www.caresearch.com.au/Portals/20/Documents/Health-Professionals/Resource.pdf>



National Palliative Care and End of Life – Aboriginal resources: <https://palliativecare.org.au/wp-content/uploads/2015/08/PCA-Palliative-care-and-Indigenous-Australians-position-statement-updated-16-8-11.pdf>

Final Footprints, My Culture, My Kinship, My Country:
<https://palliativecare.org.au/final-footprints-my-culture-my-kinship-my-country/>

Education

Aboriginal Cultural eLearning – a healthier future. Government of Western Australia. Department of Health: <https://ww2.health.wa.gov.au/Improving-WA-Health/About-Aboriginal-Health/Aboriginal-cultural-learning/Aboriginal-Cultural-eLearning-a-healthier-future>

Journey of health and wellbeing. Government of Western Australia. Department of Health:
<https://www.youtube.com/watch?v=cDYGjkcjUdg>

Palliative and Supportive Care Education (PaSCE). Cancer Council WA: <https://www.cancerwa.asn.au/professionals/pasce/>

Culturally appropriate palliative care in the West Kimberley – a film developed by Cancer Council WA's Palliative and Supportive Care Education (PaSCE) team in partnership with the Yiriman Project: <https://www.youtube.com/watch?v=gA9Tu2590OI>

Cultural Awareness Training. Rural Health West: <https://www.ruralhealthwest.com.au/about-us/cultural-awareness-training>

Aboriginal and Torres Strait Islander Health Professional education. Program of Experience in the Palliative Approach (PEPA):
<https://pepaeducation.com/support-and-education/palliative-approach-to-care-for-aboriginal-and-torres-strait-islander-health-workers/>
<https://pepaeducation.com/placements/health-professionals/aboriginal-and-torres-strait-islander-health-professionals/>

Gwandalan Palliative Care Project: an education and training suite for health professionals supporting palliative care for Aboriginal and Torres Strait Islander communities: <https://gwandalanpalliativecare.com.au/>



Advance care planning

Advance Care Planning, A Brochure for the Aboriginal Community of Western Australia:

https://ww2.health.wa.gov.au/sitecore/content/Healthy-WA/Articles/A_E/Advance-care-planning

Dying to Talk. Aboriginal and Torres Strait Islander Discussion Starter. Palliative Care Australia Ltd:

<https://dyingtotalk.org.aulaboriginal-torres-strait-islander-discussion-starter/>

Respecting Patient Choices: Advance care yarning for Aboriginal and Torres Strait Islanders. South Australia: Government of South Australia: https://www.swslhd.health.nsw.gov.au/Carers/content/pdf/Advance_care_yarning.pdf

Advance Care Planning Australia. Taking Control of Your Health Journey: <https://www.advancecareplanning.org.au/docs/default-source/acpa-resource-library/acpa-publications/taking-control-of-your-health-journey.pdf?sfvrsn=12>

Caring for your mob at the end of their life: My end of life care. Talking about what matters to me. Australian Government Department of Health: <https://www.health.gov.au/sites/default/files/caring-for-your-mob-at-the-end-of-their-life.pdf>

Respecting Patient Choices: Advance Care Planning with Aboriginals and Torres Strait Islanders. Austin Health:

https://www.caresearch.com.au/Caresearch/Portals/0/Documents/WhatisPalliativeCare/NationalProgram/RespectingPtChoices/Aboriginal_Torres_Strait_Islander_Advance_Care_Planning%20.pdf



Glossary and acronyms

Aboriginal Community Controlled Health Organisations (ACCHOS)	An Aboriginal Community Controlled Health Organisation (ACCHO) is a primary health care service initiated and operated by the local Aboriginal community to deliver holistic, comprehensive, and culturally appropriate health care to the community, which controls it (through a locally elected Board of Management) ²³ .
Aboriginal Health and Wellbeing	Aboriginal health and wellbeing is more than the physical wellbeing of an individual. It refers to the social, emotional and cultural wellbeing of the whole community in which everyone can achieve their full potential as a human being thereby bringing about the total wellbeing of their community. It is a whole of life view and includes the cyclical concept of life-death-life ² .
AHLO	Aboriginal Health Liaison Officer.
AHP	Aboriginal health professional.
AHW	Aboriginal health worker.
Advance Care Planning	A voluntary process of planning for future health and personal care whereby the person's values, beliefs and preferences are made known to guide decision-making at a future time when that person cannot make or communicate their decisions.
Advance Health Directive	An Advance Health Directive is a legal document completed by an adult with full legal capacity which contains decisions regarding future treatment. It specifies the treatment(s) for which consent is provided or refused under specific circumstances.
Cultural safety	Cultural safety focuses primarily on systemic change that seeks to assist health professionals to integrate culture into their delivery of programs and services, and to adopt a cultural lens to view practices from the perspective of Aboriginal people and culture. The emphasis is that the responsibility for the provision of culturally safe health care lies with the system and not just the individual health practitioner ² .
Cultural respect	The recognition, protection and continued advancement of the inherent rights, cultures and traditions of Aboriginal people. Cultural respect is about shared respect. It is achieved when the health system is a safe environment for Aboriginal people and where cultural differences are respected ² .



Glossary and acronyms continued

End-of-life	End-of-life is the timeframe during which a person lives with, and is impaired by, a life-limiting/fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end-of-life will be considered likely to die during the next 12 months ¹ .
End-of-life care	End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers ¹ .
Metropolitan Palliative Care Consultancy Service (MPaCCS)	MPaCCS is a palliative care service that works with staff and people in residential care facilities, psychiatric facilities, disability services and other facilities where palliative care may not be the core business ²⁴ .
WA Regional Specialist Palliative Care Services	WA Country Health Service rural and regional specialist palliative care teams providing services across the seven regions of country WA ²⁵ .
Palliative care	Palliative care is an approach that improves the quality of life of individuals, their families and carers facing problems associated with life-threatening illness/condition, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family/carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes ¹ .
Specialist Palliative Care	Specialist Palliative Care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. They provide direct care to people, and their family/carer with complex palliative care needs and/or provide consultation services to support, advise and educate specialist and non-specialist teams providing end of life care ¹ .
Terminal care	Terminal care is care of a person in the last days or hours of life ¹ .



Glossary and acronyms continued

Chronic disease	A chronic disease is a long-lasting condition that cannot be cured however it can be managed with appropriate medication, medical supervision and frequently with the assistance of lifestyle interventions.
Coronial investigation	A coronial inquest is a public inquiry to determine the identity of a dead person, how they died, and the place, date and cause of their death. In Western Australia, such inquests are conducted by a coroner under the <i>Coroner's Act 1996</i> .
Custodian	A person who has responsibility to take care of or to protect something e.g. a family.
Country	The particular land area to which an Aboriginal person is connected.
Family	Immediate family – An individual's mother, father, brother or sister. Immediate and extended family – relations of people to an individual family. Mob – an Aboriginal term referring to family or traditional group.
Dreaming	The Dreamtime is the period in which life was created according to Aboriginal culture. Dreaming is the word used to explain how life came to be; it is the stories and beliefs behind creation. The Dreaming also commands the rules and ways of being in Aboriginal culture.
Holistic	All-inclusive person-centred care that encompasses physical, emotional, psychological, and spiritual care.
Lore	Aboriginal cultural heritage and practices.
TSI	Torres Strait Islander groups and individuals.
Finished/Passed away	A term used to describe dying/death.
Sad News	Aboriginal term for death and dying.
Sorry Business	Encompasses what Aboriginal people need to do around death dying.
Elder	An Elder is a member of the Aboriginal community who carries cultural knowledge and great wisdom regarding the Lore.



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Artwork

Thank you to the Yiriman Women's Art Project. The Yiriman Women Bush Enterprises (<https://www.yirimanwomen.org/about/>) is a social enterprise project focusing cultural health, bush foods, art, design, on Country experiences in the Kimberley, Western Australia. This piece was created as part of a series of workshops centred around death and dying.

Artist: Wendy Waye

Description: Here we are caring for a really sick one who can't be fixed or might be dying. This is for when the medical boss (maybe a doctor or a nurse) says, "Oh, that person, can't make it now". Then family may say "We are keeping them" and ask for them back – "We gonna look after this one". Then they "sit down" and talk it through.



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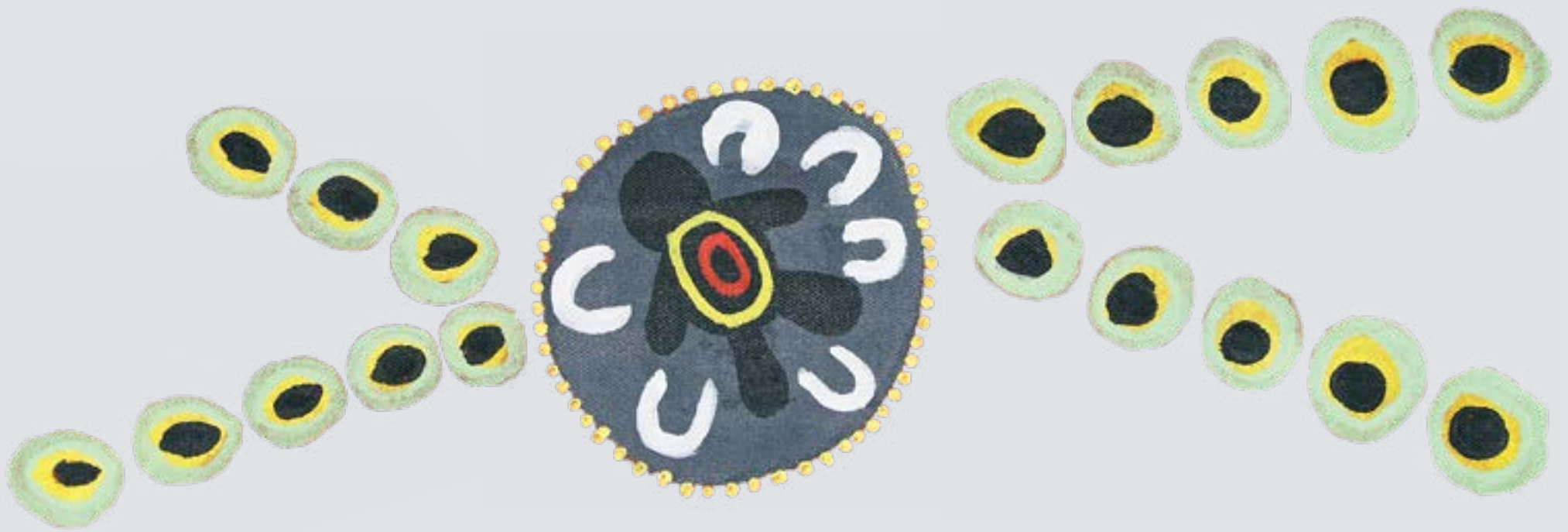
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