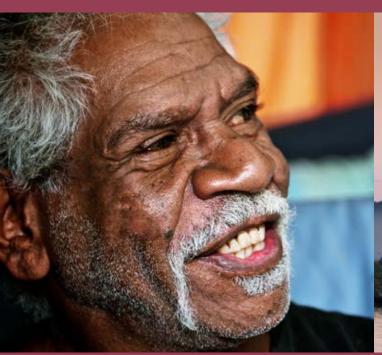
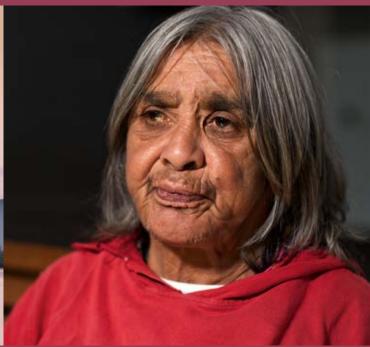


Supporting Inclusive End of Life Care: Older Aboriginal and/or Torres Strait Islander Peoples





















About this document

Acknowledgements

ELDAC acknowledges the Traditional Custodians of the many ancestral lands and waters throughout Australia. We recognise the knowledge, strength and resilience of Aboriginal and Torres Strait Islander Peoples, and their continuing spiritual and cultural connections to land, water and community. ELDAC pays respect to Elders past, present and emerging.

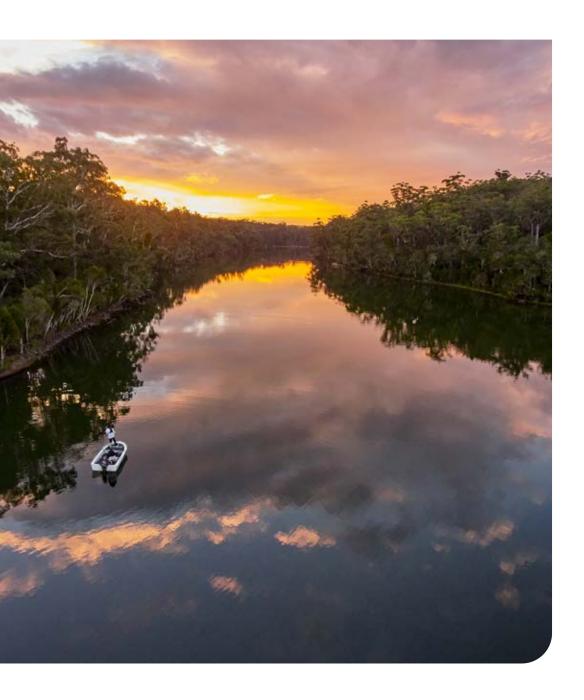
This companion guide aligns with the Australian Government Department of Health *Aged Care Diversity Framework and Actions to Support Older Aboriginal and/or Torres Strait Islander People: A Guide for Aged Care Providers.* This resource is supported by the Department of Health and uses excerpts from the *Actions to Support Older Aboriginal and/or Torres Strait Islander People: A Guide for Aged Care Providers.*

The ELDAC team thank the following organisations/groups for reviewing this resource:

- Australian Government Department of Health
- The National Palliative Care Australia Yarning Circle.

Cultural sensitivity

Aboriginal and/or Torres Strait Islander Peoples should be aware that this document may contain images or voices of Aboriginal and/or Torres Strait Islander Peoples who have passed away. Please be advised that this document provides information and discussion on an important, but sensitive topic about palliative care, death and dying/finishing up, and sorry/sad business.



ELDAC disclaimer

- The ELDAC Project Team attempted to ensure the information in this resource is as accurate and complete as possible at the time of publishing. The information may change from time to time as further research is conducted and new guidelines become available.
- Practice may also vary according to what is available locally and the experience and expertise of health professionals. The information provided is of a general nature, and best judgement should be used when putting it into practice.
- Seek independent professional advice as required. Further information on the terms and conditions of the use of ELDAC products are available on the ELDAC website. [1]
- The views and opinions expressed in this resource are not necessarily those of the Australian Government Department of Health and Aged Care.

Suggested citation

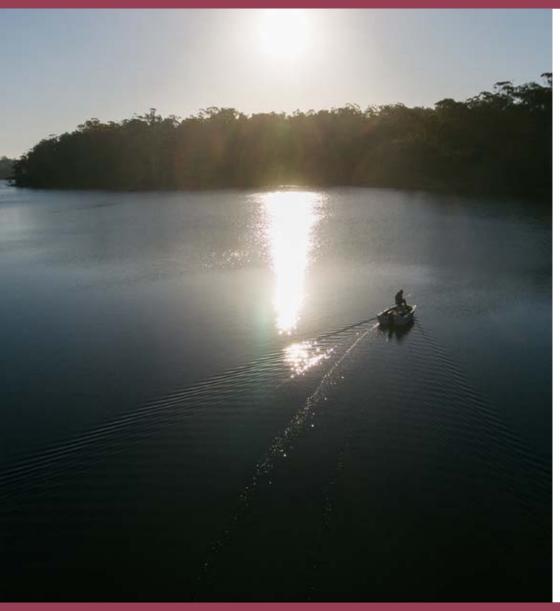
The ELDAC team at the University of Technology Sydney (UTS) developed this resource and the related ELDAC Diverse Populations suite of resources. The recommended citation for this resource:

End of Life Directions for Aged Care (ELDAC). Supporting Inclusive End of Life Care: Older Aboriginal and/or Torres Strait Islander Peoples. 2022. Available from: www.eldac.com.au

Enquires

For any enquires regarding this companion guide or the related ELDAC Diverse Populations suite of resources, please go to the ELDAC website at www.eldac.com.au or contact eldac.project@flinders.edu.au

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Introduction



Supporting Inclusive End of Life Care: Older Aboriginal and/or Torres Strait Island Peoples is a resource focused on quality improvement activities. This resource enables aged care providers to review and reflect on their organisational capacity to support advance care planning, and provide quality palliative care that is culturally safe and inclusive.

This resource has been developed in consultation with key stakeholders and provides useful information, guidance and links to key resources. It was developed to be used as a companion guide that builds on essential aged care documents described below that were published by the Australian Government Department of Health.

Aged Care Diversity Framework

The Aged Care Diversity Framework (the Framework) was launched in 2017 and aims to ensure the aged care system is accessible, inclusive, and meets the care needs of all older Australians from diverse backgrounds. [2, 3] The framework outlines the challenges for some people to access the aged care they need, and what improvements can be achieved to remove these barriers, and provide quality care that is respectful and inclusive.

Guides for aged care providers (Action Plans)

There are four distinct guides for aged care providers (Action Plans) [4] developed under the Framework that supports providers addressing the diverse care needs of all older Australians:

- Shared Actions to Support all Diverse Older People, which is an overarching set of actions in recognition of the many commonalities within and between diverse groups; [5]
- Actions to Support Older Culturally and Linguistically Diverse People; [6]
- Actions to Support Older Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders; [7]
- Actions to Support Older Aboriginal and Torres Strait Islander **People**. [8]

The Framework [3] and Action Plans [4] were developed by the Aged Care Sector Committee Diversity Sub-group. The collection of Action Plans also includes a government Action Plan [9] and Actions Plans designed specifically for consumers from diverse backgrounds; such as the Actions to Support Older Aboriginal and Torres Strait Islander People: A Guide for Consumers. [10]

The set of aged care provider Action Plans outlines six key outcomes for consumers, which provides a guide for assessing current performance, identifying gaps, addressing barriers, and designing pathways to improve inclusive service provision.

Key outcomes for consumers

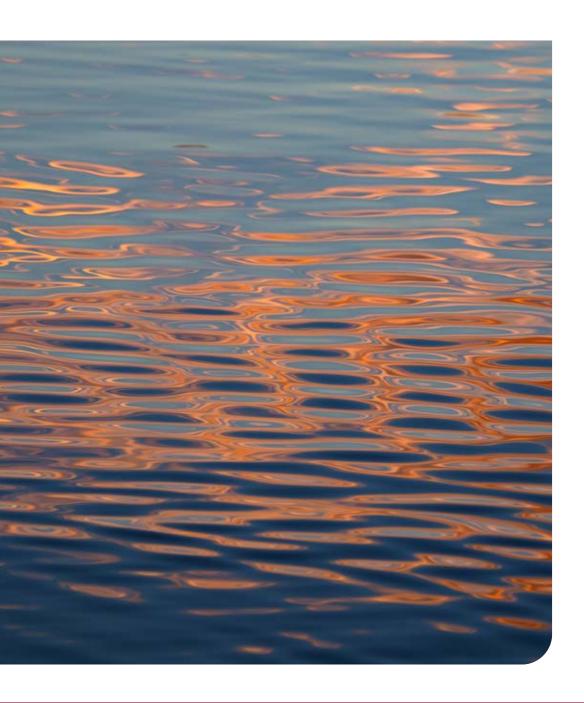
- 1. Making informed choices
- 2. Adopting systemic approaches to planning and implementation
- 3. Accessible care and support
- 4. A proactive and flexible aged care system
- 5. Respectful and inclusive services
- 6. Meeting the needs of the most vulnerable

The Action Plans acknowledge that there is no 'one-size-fits-all' approach to diversity, and that each provider will be starting from a different place and operating in a different context. The Action Plans are designed so that providers can work through the three levels of actions listed below.

Levels of Actions

- 1. Foundational Actions
- 2. Moving Forward
- 3. Leading the Way

Providers can decide which actions are most relevant to their organisation in consultation with consumers, their support people, and staff. Each consumer outcome has example actions to support providers in the provision of aged care. The Action Plans also include case study examples for supporting the care needs of older people from diverse backgrounds.



How to use this companion guide

This resource should be used in conjunction with the *Aged Care Diversity Framework* (the Framework) [3] and the *Actions to Support Older Aboriginal and Torres Strait Islander People: A Guide for Aged Care Providers* (the Action Plan) [8] when reviewing end of life care needs for older Aboriginal and/or Torres Strait Islander Peoples.

Each of the six key outcomes for consumers from the Action Plan are listed below with ELDAC recommended actions specifically for supporting inclusive end of life care. The actions align to the three levels of actions in the Action Plan: Foundational Actions, Moving Forward, and Leading the Way. The references and key resources are listed in the Appendices.

"Attention to culture and its impact on health care can improve the quality of care given, add to our understanding of health care among culturally diverse populations, and encourage a more holistic approach to health care within general care. Connection to culture is important to Aboriginal peoples, and integrating Aboriginal culture into general care in residential aged care facilities may contribute to improving care delivery and outcomes for residents." [11]

1. Making informed choices

Outcome for consumers

Older people have easily accessible information about the aged care system and services that they understand and find the information helpful to exercise choice and control over the care they receive.

Actions for aged care providers

Provide information in an appropriate format, through different forms (online/hardcopy/newsletter/verbal) and in a language the consumer understands.

Actions for aged care providers in supporting inclusive end of life care

Foundational Actions

- Using a co-design approach, establish partnerships with local Aboriginal and/or Torres Strait Islander and palliative care services to work together to share and disseminate information with individuals, families, and communities about end of life care.
- Develop policies and practices to ensure end of life care discussions and the palliative care assessment process are culturally responsive, safe, and inclusive. [12] Ensure Aboriginal and/or Torres Strait Islander Peoples feel empowered to involve chosen family and/or community members, and interpreter services as required, to support them through end of life care. [13]

Moving Forward

- Through education and training ensure that Aboriginal and/or Torres
 Strait Islander Peoples are treated with dignity and respect; their identity
 is valued; they feel that they belong and are being supported; and
 are able to exercise choice and control in decisions about their end
 of life care. [14]
- Support staff to provide culturally aware grief and bereavement support for family and community members, sometimes referred to as Sorry Business, a period of cultural practices following the death of a community member. [15]

Leading the Way

 Recognise that cultural safety is the most critical aspect of person-centred care for Aboriginal and/or Torres Strait Islander Peoples. Work with local Aboriginal and/or Torres Strait Islander providers to develop culturally relevant advance care planning and palliative care resources.

"NACCHO [National Aboriginal Community Controlled Health Organisation], its affiliates and member services are keenly aware that developing a culturally safe model of care involves taking the time to develop relationships with Aboriginal and Torres Strait Islander Peoples based on trust and respect. Without trust, our people will not engage with services or feel comfortable about discussing their care preferences." [16]

2. Adopting systemic approaches to planning and implementation

Outcome for consumers

Older people are active partners in the planning and implementation of the aged care system.

Actions for aged care providers

Engage consumers in a culturally safe, supportive environment that enables them to participate as active partners, as well as articulate their individual needs.

Actions for aged care providers in supporting inclusive end of life care

Foundational Actions

 Through meaningful engagement and consultation with local Aboriginal and/or Torres Strait Islander communities, establish a palliative care and advance care planning working group to co-design, deliver, and evaluate advance care planning and palliative care that is culturally relevant and consistent with the Aboriginal model of health.

Moving Forward

 With the working group, conduct an ELDAC Advance Care Planning and Palliative Care Organisational Audit [17, 18], to inform planning and implementation of culturally safe and responsive end of life care. This includes providing for end of life care on country, where possible, in accordance with the person's end of life care wishes. [19]

Leading the Way

 Deliver and evaluate advance care planning and palliative care that acknowledges that although many Aboriginal and/or Torres Strait Islander Peoples have been relocated, and no longer live on traditional country, this does not diminish cultural and spiritual connections to country.

"Aboriginal people traditionally regarded the land as spiritual, staying within their own country, identified by a group or tribal name. Despite many Aboriginal people living in cities and regional areas and not remote and isolated areas, these beliefs and values have prevailed over many thousands of years."
[20, 21, 22]

3. Accessible care and support

Outcome for consumers

Older people in rural, remote, regional and metropolitan Australia have access to aged care services and supports appropriate to their diverse characteristics and life experiences.

Actions for aged care providers

Collaborate with stakeholders to identify and overcome barriers in accessing the aged care system.

Actions for aged care providers in supporting inclusive end of life care

Foundational Actions

• Through education and policies promote end of life care that ensures the basic human rights of Aboriginal and/or Torres Strait Islander Peoples to have their cultures respected.

Moving Forward

• Form partnerships and work closely with other service providers to improve referral process and continuity of care, especially Aboriginal Medical Services, specialised palliative care, mental health and/or healing services, and community cultural organisations.

Leading the Way

• Through organisational leadership develop co-designed policies and processes that facilitate trauma-informed palliative care and discussions about end of life care with Stolen Generations survivors, and others impacted by trauma or with particular vulnerabilities. [23]

"The trauma associated with severance of parental and family relationships, the added alienation from culture and the attempted erasure of Aboriginality, has had a severe and lasting impact on Stolen Generations survivors and their descendants." [24]

4. A proactive and flexible aged care system

Outcome for consumers

A proactive and flexible aged care system that responds to the needs of existing and emerging diverse groups, including an increasingly diverse aged care workforce.

Actions for aged care providers

Engage with the local community and stakeholders to identify emerging needs and how service delivery models can be adapted to embrace those needs, including how the organisation's workforce demonstrates an inclusive approach to care.

Actions for aged care providers in supporting inclusive end of life care

Foundational Actions

• Work in partnership with local Aboriginal and/or Torres Strait Islander organisations, including Aboriginal community-controlled organisations, to ensure organisational policies, education and training support end of life care practices and reflect the cultural values, practices, and beliefs of Aboriginal and/or Torres Strait Islander Peoples.

Moving Forward

• Conduct an analysis of the local population to proactively plan and prepare for palliative care service delivery needs, including Stolen

Generations survivors, many of whom are over 50 years of age. Build the capabilities of the workforce to provide trauma-informed end of life care in response to projected demand. [25, 26]

Leading the Way

• Through proactive planning and strong leadership, provide end of life care that recognises that some Aboriginal and/or Torres Strait Islander Peoples are Stolen Generations survivors and the complexity of their needs means that no single model of care will be universally relevant. Care should be guided by principles of self-determination, choice, trauma aware, healing informed, trust and be holistic. [27, 28]

"Culturally appropriate methods of engaging Aboriginal People in ACP [Advance Care Planning] discussions should include Aboriginal health workers and take a whole of community approach to awareness raising." [29]

5. Respectful and inclusive services

Outcome for consumers

Services effectively meet the specific needs of older people with diverse characteristics and life experiences, their families, carers and representatives in a respectful and inclusive way.

Actions for aged care providers

Seek out, develop and use tools, training and information that support delivery of care that is inclusive of diverse characteristics and life experiences.

Actions for aged care providers in supporting inclusive end of life care*

Foundational Actions

- Through meaningful engagement and consultation with local Aboriginal and/or Torres Strait Islander communities, identify how best to include informal care givers in the provision of culturally and spiritually safe end of life care that is respectful and inclusive.
- As part of your organisation's Reconciliation Action Plan, commit to acknowledging and celebrating cultural events by bringing culture and country to the Aboriginal and/or Torres Strait Islander Peoples in your organisation's care. For example, celebrate NAIDOC week to ensure Aboriginal and/or Torres Strait Islander Peoples experience dignity and quality of life at the end of their lives. [30]

Moving Forward

- Through strong leadership and governance, commit to workforce development strategies to build cultural understandings. Support culturally safe and responsive advance care planning and palliative care through access to the Program of Experience in the Palliative Care Approach (PEPA) [31] and Indigenous Program of Experience in the Palliative Approach (IPEPA) [32]. Support Aboriginal Health Workers to complete palliative care training.
- Develop co-designed policies and processes to ensure staff and consumers can provide feedback about end of life care, including options for people with limited literacy.

"Acknowledging Aboriginal People's relationship rules and communicating through family meetings are practices that demonstrate respect for Aboriginal cultural processes of information sharing... Respecting the need to share the story broadly with the appropriate people in the extended family and the community through family meetings is noted as vitally important in health care, and it is especially important during the dying trajectory." [33, 34]

^{*}The Respectful and Inclusive Services Actions for Aged Care Providers section does not include a Leading the Way level of action in the Action Plan.

6. Meeting the needs of the most vulnerable

Outcome for consumers

Older people can access high quality culturally safe aged care services and supports that meet their needs irrespective of their personal, social or economic vulnerabilities.

Actions for aged care providers

Provide inclusive service models to address the needs of the most vulnerable, and work with other stakeholders to ensure that the full spectrum of needs is met.

Actions for aged care providers in supporting inclusive end of life care

Foundational Actions

• Implement culturally safe and responsive advance care planning and palliative care, with particular focus on trauma-informed care for people who have experienced trauma, including Stolen Generations survivors, and for people with particular vulnerabilities.

Moving Forward

- Work in partnership with local Aboriginal and/or Torres Strait Islander organisations to provide end of life care that recognises that culture is a source of strength, resilience, happiness, identity and confidence, and is inextricably linked to the health and well-being of Aboriginal and/or Torres Strait Islander Peoples. [35]
- Co-design facilities, services and programs with local Aboriginal community groups to develop culturally relevant and responsive palliative care.

Leading the Way

• Develop clear guidelines and policies to ensure end of life care preferences are supported. This may include decisions about referrals and transfers to receive culturally safe palliative care.

"Intergenerational trauma adversely impacts on individuals' health and socioeconomic outcomes and affects the capacities of families and communities to care for community members as they age and become frail." [16]

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