

Supporting Inclusive End of Life Care: **Older People from Culturally and Linguistically Diverse Backgrounds**



About this document

Acknowledgements

This companion guide aligns with the Australian Government Department of Health *Aged Care Diversity Framework and the Actions to Support Older Culturally and Linguistically Diverse 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 Culturally and Linguistically Diverse People: A Guide for Aged Care Providers*.

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- Australian Government Department of Health
- Centre for Cultural Diversity in Ageing (CCDA)
- Federation of Ethnic Communities' Councils of Australia (FECCA).

ELDAC disclaimer

- The ELDAC Project Team have 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 is 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:

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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 People from Culturally and Linguistically Diverse (CALD) Backgrounds 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 Aboriginal and Torres Strait Islander People*; [6]
- *Actions to Support Older Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders*; [7]
- **Actions to Support Older Culturally and Linguistically Diverse People**. [8]

The Framework [3] and Action Plans [4] were developed by the Aged Care Sector Committee Diversity Sub-group. The Federation of Ethnic Communities' Councils of Australia (FECCA) contributed to the development of the *Actions to Support Older Culturally and Linguistically Diverse People: A Guide for Aged Care Providers* (the Action Plan). [8] 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 Culturally and Linguistically Diverse 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 Culturally and Linguistically Diverse People: A Guide for Aged Care Providers* (the Action Plan) [8] when reviewing end of life care needs for older people from CALD backgrounds. 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.

“The needs of different CALD communities and individuals within those communities vary considerably. These distinct needs must be recognised and catered for in the aged care system to ensure that it has the capacity to respond to the individual person regardless of their cultural or linguistic background. All individuals are cultural beings embedded within the cultural and linguistic paradigms of their families, social groups, community, education and experiences.” [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

- Acknowledge the importance of dignity, inclusivity, and choice at end of life. Ensure consumers from CALD backgrounds have access to culturally-relevant and translated resources about advance care planning and palliative care services, and are supported to express their personal end of life care preferences.

Moving Forward

- Using a co-design approach, consult with CALD advocacy services and community groups to develop policies, resources and referral pathways that will enable older people from CALD communities to make informed end of life care decisions.

Leading the Way

- Through strong leadership commit to the recruitment of staff from CALD backgrounds and/or employment of diversity champions to strengthen organisational capacity. Provide culturally safe and inclusive palliative care for consumers from CALD backgrounds.

“People will have different levels of need for palliative care. People with more complex needs should be able to access care provided by specialist palliative care services comprising multidisciplinary teams with specialised skills, competencies, experience and training in palliative care.” [12]

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

- Support staff to develop skills in culturally responsive care and communication to explore the needs and preferences of consumers from CALD backgrounds, particularly in relation to recognising end of life and documenting advance care planning discussions.
- Develop co-design policies and practices that support culturally safe and inclusive end of life care so that consumers from CALD backgrounds feel empowered to involve a trusted entity or support person in the palliative care assessment process. Offer access to interpreter services as required. [13]

Moving Forward

- Establish a palliative care and advance care planning working group that includes people from CALD communities, to develop strategies, such as access to professional development to strengthen culturally inclusive palliative care provided by your organisation.

Leading the Way

- Through strong governance, ensure that consumers from CALD backgrounds are consulted about and actively participate in planning for projected palliative care service delivery needs.

“Discussing death is actively discouraged in some cultures as it is viewed as an indication of disrespect, likely to extinguish hope, invite death, and/or cause distress, depression and anxiety. Understanding each patient’s, and their family’s, cultural needs and preferences is essential to provide palliative care in a manner that conforms to their individual values and ideals.” [14, 15]

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

- Consult with local community groups to identify cultural needs and preferences for end of life care for different cultural groups.
- Ensure people from diverse backgrounds experience dignity and quality of life at the end of their lives, especially for people with particular vulnerabilities.

Moving Forward

- Conduct a demographic assessment of the local region to identify people from CALD backgrounds and other diverse communities. Partner with local services to co-design and plan for end of life care services to meet emerging population needs.

Leading the Way

- In partnership with CALD organisations and community groups identify strategies to support families and carers of people in their last year of life. For example, providing a space for family discussions that represents the diversity of consumers.

“Around the country, relationships between palliative care peak bodies, providers and CALD communities are being explored and developed to improve understanding of, and access to, palliative care. These relationships and networks are raising awareness at the community level and improving the capacity of service providers to deliver culturally-appropriate care. Relevant networks (e.g. involving palliative care services, Primary Health Networks, other services and community groups) have the potential to help build both community and sector capacity to improve access to culturally appropriate palliative care.” [16]

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

- Engage with carers from CALD backgrounds in the community to share their lived experiences of palliative care with staff highlighting what worked well for them including: bereavement care and support; recognition of cultural beliefs; and participation in end of life decision making.
- Encourage staff to seek feedback from older people from CALD backgrounds in a culturally inclusive way that acknowledges language, literacy, and cultural considerations.

- Recognise the influences of ethnicity, religion, sexual orientation, gender, socio-economic factors, disability, age, pre-migration experiences, migration status, and/or experience of trauma. Commit to ensuring all staff are provided with access to professional development opportunities to deliver culturally safe and inclusive palliative care in aged care settings.

Moving Forward

- Complete an ELDAC Advance Care Planning and Palliative Care and Organisational Audit [17, 18] with the aim of identifying measurable outcomes for end of life care for older people from CALD communities, including early referrals to specialist palliative care as required.

Leading the Way

- Demonstrate organisational leadership and support for consumers from CALD backgrounds including their diverse characteristics and life experiences by embedding a culture of inclusion across the organisation.

"Education about cultural diversity is recommended for aged care teams to enhance an understanding of care preferences of individuals from different cultural backgrounds. Efforts to accommodate these preferences promote individualised care which benefits individuals and their families." [19]

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

- In partnership with CALD organisations and community groups commit to acknowledging and celebrating festivals and cultural events, such as Harmony Week.
- With a focus on improving quality at end of life, identify different foods and cultural traditions that align with the cultural diversity of consumers in the local region.

Moving Forward

- Using a co-design approach, provide or develop resources that support older people from CALD backgrounds to make end of life care decisions that are shared and involve family and community, contrary to a more individualist approach to advance care planning. [20]

Leading the Way

- Recognise that many older people from CALD communities have experienced traumatic events such as war, financial hardship, and torture. Commit to implementing trauma-informed approaches to end of life care and service delivery. [21]

“Clinicians should consider language, literacy and health literacy when working with people from migrant and refugee backgrounds. Lack of capacity to communicate effectively in healthcare settings and low levels of general and health literacy affect a person’s ability to assess the information provided and to reach a decision.” [22, 23]

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

- In consultation with local leaders and community groups, identify how best to provide culturally safe and inclusive advance care planning and palliative care.

Moving Forward

- Ensure organisational policy supports culturally safe, responsive and trauma-informed palliative care, especially for people with particular vulnerabilities.
- Co-design facilities, services and programs with local CALD community groups to develop culturally relevant and responsive palliative care.

Leading the Way

- Employ bi-lingual and bi-cultural staff that reflect the cultural and language demographic of consumers at your service, and support them to provide safe and inclusive palliative care.

“The aged care system must be accessible and fair to all. For culturally and linguistically appropriate care to be provided, organisations and staff must recognise and respond to individuals of all cultural and linguistic backgrounds.” [24]

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