

Supporting Inclusive End of Life Care: **Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders**



About this document

Acknowledgments

This companion guide aligns with the Australian Government Department of Health *Aged Care Diversity Framework and Actions to Support Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders: A Guide for Aged Care Providers*. This resource is supported by the Department of Health and uses excerpts from the *Actions to Support Lesbian, Gay, Bisexual, Trans and Gender Diverse and Intersex Elders: A Guide for Aged Care Providers*.

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

- Ageing with Pride
- Australian Government Department of Health
- Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University
- LGBTIQ+ Health Australia (formerly the National LGBTI Health Alliance)
- Rainbow Health Victoria

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:

End of Life Directions for Aged Care (ELDAC). Supporting Inclusive End of Life Care: Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders. 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

Contents



Introduction	4
Aged Care Diversity Framework	4
Guides for aged care providers (Action Plans)	5
How to use this Companion Guide	6
1. Making informed choices	7
2. Adopting systemic approaches to planning and implementation	8
3. Accessible care and support	9
4. A proactive and flexible aged care system	10
5. Respectful and inclusive services	11
6. Meeting the needs of the most vulnerable	12
Appendix 1: References	13
Appendix 2: Resources	16

Introduction



Supporting Inclusive End of Life Care: Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders 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 Culturally and Linguistically Diverse People*; [7]
- ***Actions to Support Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders***. [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 Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders: 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 Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders: A guide for aged care providers* (the Action Plan) [8] when reviewing end of life care needs for older people who identify as LGBTI*. 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 acronym LGBTI is used throughout this companion guide recognising and encompassing all people who identify as lesbian, gay, bisexual, trans and gender diverse, and/or intersex.*

"Providing effective, high-quality care for someone during the end of their life is challenging. Without support and information, practitioners, staff and carers can find the experience overwhelming. Identifying end of life care needs at an early stage is beneficial and can allow more time to plan appropriate support needs effectively with and for someone." [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

- Ensure LGBTI consumers have access to LGBTI inclusive information about advance care planning and palliative care services by increasing LGBTI visibility in these resources (including written content and images) and having resources available from LGBTI organisations. Ensure that the resources cover and reflect the different and sometimes overlapping needs of people from each of the different identities.

Moving Forward

- Using a co-design approach, work with LGBTI advocacy services and community groups to develop policies, resources and actions that ensure dignity and choice at end of life that will enable LGBTI people to make informed end of life care decisions that include their families of choice and carers. [12]

Leading the Way

- Through strong leadership establish a palliative care and advance care planning working group that includes LGBTI people to review, reflect, and strengthen organisational capacity to support advance care planning and provide palliative care for LGBTI consumers.

"The current generation of LGBTI older people requires particular attention when interfacing with health care, as they are likely to have experienced high levels of discrimination, prejudice, and possibly violence during their lifetime." [13]

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

- Commit to completing an ELDAC Advance Care Planning and Palliative Care Organisational Audit [14, 15] with the aim of identifying strategies to strengthen LGBTI culturally safe and inclusive end of life care that respects the person's family of choice, and care needs throughout their end of life care journey. [16]
- Through governance and policies, commit to understanding the needs of LGBTI consumers, particularly in relation to end of life care planning and needs.

Moving Forward

- With a focus on trauma-informed care, co-design policies, procedures and practices with LGBTI people and advocacy services that meet the end of life care needs of LGBTI people, and the unique palliative care needs of people living with HIV. [16, 17]

Leading the Way

- Ensure that LGBTI consumers are consulted about and actively participate in planning for projected palliative care service delivery needs. [18]

"LGBTI people potentially face multiple obstacles to having their healthcare wishes respected at the end of life; years of discrimination, coupled with sometimes aggressive intrusion from biological family members." [19]

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

- Commit to ensuring staff understand the importance of including partner/s and families of choice in conversations about palliative care needs, and providing support for families and carers.

Moving Forward

- Ensure organisational policy supports culturally safe, responsive, and trauma-informed palliative care, particularly for LGBTI people and other vulnerable populations. [20]

Leading the Way

- With LGBTI organisations co-design, deliver and evaluate workforce development and capacity building strategies to ensure staff provide LGBTI safe and inclusive end of life care. Provide opportunities to consumers to disclose if they feel safe to do so. Ensure that people have multiple opportunities to do this as it may take time to build trust.

"It is important service providers understand that history has diminished some LGBT people's sense of entitlement. It is also important to be mindful of historical experiences of discrimination when undertaking assessment or developing life stories. Questions about experiences growing up, family and early relationships may precipitate anxiety or be re-traumatising." [21]

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 LGBTI carers to share their lived experiences of palliative care with staff, highlighting what worked well for them including: bereavement care and support; inclusion of family and friends; recognition of friendships; and their rights in end of life decision making.
- Support access to professional development opportunities to assist staff in providing LGBTI-inclusive, holistic, and person-centred end of life care for LGBTI people and their families of choice. [16]

- Provide educational resources and training so that staff understand why some LGBTI consumers, including those people living with HIV, may be very private and hesitant to disclose information about their sexual orientation, intersex variation, gender identity and/or body. [16]

Moving Forward

- Consult with local LGBTI organisations to identify optimal strategies to support LGBTI people at end of life and develop an organisational plan to implement these strategies.

Leading the Way

- Demonstrate organisational leadership and support for LGBTI consumers and their diverse characteristics and life experiences. Provide a welcoming environment and display LGBTI-inclusive advance care planning and palliative care resources and explicit markers of inclusion; such as rainbow lanyards for staff who have completed LGBTI inclusivity training and have been assessed as inclusive.

"Organisations can also ensure they have clear and explicit guidelines on LGBTI-inclusive practice, ongoing education for all staff (regardless of their role) about all the components of cultural safety and specific reference to expectations of LGBTI-inclusive service delivery throughout recruitment processes." [22]

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

- Using a co-design approach, develop policies and processes to promote respectful and inclusive end of life care, including the promotion of trauma-informed care, particularly for gender diverse and intersex people.

Moving Forward

- Consult with local LGBTI people to co-design clear policies and procedures related to any issues or discrimination. This includes strategies to promote LGBTI inclusive practice and to support LGBTI people, and their carers, to confidently provide feedback on their experiences and interactions with staff providing end of life care.

Leading the Way

- Provide access to resources for all staff that includes legal considerations at end of life. [23]
- Through local community of practice, provide opportunities for staff to reflect on their attitudes and beliefs.

“Simple changes to practice could markedly improve care experiences for LGBT people, including avoiding heterosexually framed, assumption-laden, questions; sensitivity in exploration of identity; careful exploration of intimate relationships; and explicit inclusion of partners or significant others.” [24]

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 LGBTI-culturally safe and inclusive advance care planning and palliative care, with particular focus on trauma-informed care for people who have experienced discrimination. Also, for those people who lost friends, family, and partners due to the HIV/AIDS epidemic.

Moving Forward

- Ensure staff are provided with education and resources to support the provision of inclusive end of life care to LGBTI consumers.
- In partnership with LGBTI advocacy services and community groups, develop co-designed policies, practices, and resources that will alleviate the risk of trauma at end of life. Ensure that staff have the communication and empathy skills to establish trust and understand the experiences of older LGBTI people, especially for people who identify as gender and/or trans diverse; have intersex variation; and/or people with particular vulnerabilities. [25]

Leading the Way

- Identify current practice and plan for continuous improvements by developing systems, policies, and practices that reflect belonging, intersectionality, and recognise the spiritual and cultural needs of older LGBTI people. [26]
- Develop clear guidelines and policies to ensure end of life care needs are supported. [27] This may include decisions about referrals and transfers to receive LGBTI-safe and inclusive palliative care. [28]

“Among the major determinants that contribute to inequalities in LGBTI people’s health are negative social attitudes, including those of health providers.” [29]

Appendix 1: References

1. End of Life Directions for Aged Care (ELDAC). **ELDAC Website Terms and Conditions** [Internet]. 2 March 2021. [cited 31 May 2022].
2. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Aged Care Diversity Framework Initiative** [Internet]. 19 January 2022. [cited 31 May 2022].
3. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Aged Care Diversity Framework** 2017 [Internet]. Canberra: Australian Government Department of Health, December 2017. [cited 31 May 2022]. Publications Number: 12028.
4. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Aged Care Diversity Framework Action Plans** [Internet]. 21 June 2021. [cited 31 May 2022].
5. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Shared Actions to Support all Diverse Older People: A Guide for Aged Care Providers** 2019 [Internet]. Canberra: Australian Government Department of Health, February 2019. [cited 31 May 2022]. Publications Number: 12164.
6. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Actions to Support Older Aboriginal and Torres Strait Islander People: A Guide for Aged Care Providers** 2019 [Internet]. Australian Government Department of Health, February 2019. [cited 31 May 2022]. Publications Number: 12164.
7. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Actions to Support Older Culturally and Linguistically Diverse People: A Guide for Aged Care Providers** 2019 [Internet]. Australian Government Department of Health, February 2019. [cited 31 May 2022]. Publications Number: 12164.
8. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Actions to Support Older Lesbian, Gay, Bisexual, Trans and Gender Diverse, and Intersex Elders: A Guide for Aged Care Providers** 2019 [Internet]. Australian Government Department of Health, February 2019. [cited 31 May 2022]. Publications Number: 12164.
9. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Australian Government Diversity Action Plan** 2019 [Internet]. Australian Government Department of Health, February 2019. [cited 31 May 2022].
10. Australian Government Department of Health, Aged Care Sector Committee Diversity Sub-group. **Actions to Support Older Culturally and Linguistically Diverse People: A Guide for Consumers** 2019 [Internet]. Australian Government Department of Health, February 2019. [cited 31 May 2022]. Publications Number: 12164.
11. National Health Service (NHS) National End of Life Care Programme. **The Route to Success in End of Life Care: Achieving Quality for Lesbian, Gay, Bisexual and Transgender People** 2012 [Internet]. NHS National End of Life Care Programme, 2012, reviewed June 2014, p12. [cited 5 June 2022]. Programme Ref: PB0041 A 06 12.

12. Cartwright C, Hughes M, Lienert T. End-of-life Care for Gay, Lesbian, Bisexual and Transgender People. Culture, Health & Sexuality [Internet]. 2012. [cited 4 June 2022]; 14(5): 537-548. DOI: 10.1080/13691058.2012.673639
13. Duffy F, Healy JP. A Social Work Practice Reflection on Issues Arising for LGBTI Older People Interfacing with Health and Residential Care: Rights, Decision Making and End-of-Life Care. Social Work in Health Care [Internet]. 2014. [cited 5 June 2022]; 53(6): 568-583, p577. DOI: 10.1080/00981389.2014.914119
14. End of Life Directions for Aged Care (ELDAC). Residential Aged Care Toolkit. ELDAC Advance Care Planning and Palliative Care Organisational Audit (Version 2) [Internet]. 20 May 2022. [cited 31 May 2022].
15. End of Life Directions for Aged Care (ELDAC). Home Care Toolkit. ELDAC Advance Care Planning and Palliative Care Organisational Audit (Version 2) [Internet]. 20 May 2022. [cited 31 May 2022].
16. Australian Government Department of Health and Australian HealthCare Associates (AHA). Exploratory Analysis of Barriers to Palliative Care: Issues Report on People who Identify as Lesbian, Gay, Bisexual, Transgender or Intersex September 2019 [Internet]. Canberra: Australian Government Department of Health, 9 January 2020. [cited 4 June 2022].
17. LGBTIQ+ Health Australia. Silver Rainbow: Ageing and Aged Care [Internet]. 31 May 2022. [cited 5 June 2022].
18. Palliative Care Australia (PCA). Palliative Care Service Development Guidelines 2018 [Internet]. Canberra: PCA, January 2018. [cited 3 June 2022].
19. Cartwright C, White B, Willmott L, Parker M, Williams G. Australian Doctors' Knowledge of a Compliance with the Law to End-of-Life Decisions: Implications for LGBTI Patients. Culture, Health and Sexuality [Internet]. 2018. [cited 5 June 2022]; 20(8): 845-857, p853. DOI: 10.1080/13691058.2017.1385854
20. Fleishman J, Kamsky H, Sundborg, S. Trauma-Informed Nursing Practice. The Online Journal of Issues in Nursing [Internet]. 31 May 2019 [cited 31 May 2022]; 24(2): Manuscript 3. DOI: 10.3912/OJIN.Vol24No02Man03
21. Crameri P, Barrett, C, Lambourne S, Latham JR. We are Still Gay: An Evidence Based Resource Exploring the Experiences and Needs of Lesbian, Gay, Bisexual and Trans Australians Living with Dementia 2015 [Internet]. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University, October 2015, p8. [cited 5 June 2022].
22. Crameri P, Barrett C, Latham JR, Whyte C. It is more than Sex and Clothes: Culturally Safe Services for Older Lesbian, Gay, Bisexual, Transgender and Intersex People. Australasian Journal on Ageing [Internet]. 2 October 2015 [cited 5 June 2022]; 34 (Suppl 2): 21-25, p23. DOI: 10.1111/ajag.12270
23. QUT End of Life Law in Australia. End of Life Law for Clinicians (ELLC) [Internet]. 2021. [cited 5 June 2022].
24. Bristowe K, Hodson M, Wee B, Almack K, Johnson K, Daveson BA, Koffman J, McEnhill L, Harding R. Recommendations to Reduce Inequalities for LGBT People Facing Advanced Illness: ACCESSCare National Qualitative Interview Study. Palliative Medicine [Internet]. January 2018 [cited 5 June 2022]; 32(1): 23-35, p33. DOI: 10.1177/0269216317705102



25. LGBTIQ+ Health Australia. Submissions: Royal Commission into Aged Care [Internet]. 1 July 2020. [cited 5 June 2022].
26. Val's LGBTI Ageing and Aged Care Program. LGBTI-Inclusive Practice Review Tool: For Services Supporting or Caring for Older People 2020 [Internet]. Melbourne: Rainbow Health Victoria at the Australian Research Centre in Sex, Health, & Society, La Trobe University, October 2020 [cited 4 June 2022]. DOI: 10.26181/5f728b5d9c6d2
27. End of Life Directions for Aged Care (ELDAC). Diverse Population Groups [Internet]. 30 July 2021. [cited 5 June 2022].
28. National LGBTI Health Alliance and Palliative Care Australia (PCA). Palliative Care for Lesbian, Gay, Bisexual, Transgender People and People with Intersex Characteristics (LGBTI): Position Statement 2015 [Internet]. Canberra: PCA, October 2015. [cited 5 June 2022].
29. National LGBTI Health Alliance. Cultural Competency Implementation Framework: Achieving Inclusive Practice with Lesbian, Gay, Bisexual, Trans and Intersex (LGBTI) Communities 2013 [Internet]. Sydney: National LGBTI Health Alliance, October 2013. [cited 5 June 2022], p4.

Appendix 2: Resources

- Australian Government Aged Care Quality and Safety Commission. Charter of Aged Care Rights 1 July 2019 [Internet]. Canberra: Australian Government Department of Health and Aged Care Quality and Safety Commission, 6 May 2022 [cited 31 May 2022].
- CareSearch. Lesbian, Gay, Bisexual, Transgender and Intersex [Internet] 02 August 2021. [cited 4 June 2022]
- Darlington Statement. Darlington Statement March 2017 [Internet]. 2021. [cited 5 June 2022]
- Dementia Support Australia and LGBTIQ+ Health Australia. LGBTI and Dementia: Understanding Changes in Behaviour [Internet]. Sydney: HammondCare, 2022 [cited 4 June 2022].
- End of Life Directions for Aged Care (ELDAC). Home Care Toolkit. Advance Care Planning [Internet]. 9 May 2022. [cited 31 May 2022].
- End of Life Directions for Aged Care (ELDAC). Residential Aged Care Toolkit. Advance Care Planning [Internet]. 9 May 2022. [cited 31 May 2022].
- End of Life Directions for Aged Care (ELDAC). Diverse Population Groups. Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) [Internet]. [Internet]. 29 July 2021. [cited 31 May 2022].
- LGBTIQ+ Health Australia. Inclusive practice. Understanding the Differences: Lesbian, Gay, Bisexual, Transgender and Intersex People [Internet]. 2022. [cited 5 June 2022].
- LGBTIQ+ Health Australia. Aged Care Inclusive Practice Poster [Internet]. 2022. [cited 4 June 2022].
- LGBTIQ+ Health Australia. Best Practice in Co-design [Internet]. 2022. [cited 4 June 2022].
- LGBTIQ+ Health Australia. LGBTIQ+ Health Australia [Internet]. 2022. [cited 4 June 2022].
- LGBTIQ+ Health Australia. Palliative Care 11 Tips Poster [Internet]. 2022. [cited 4 June 2022].
- Program of Experience in the Palliative Care Approach (PEPA). PEPA [Internet]. 2022. [cited 3 June 2022].Appendix 2: Resources

