

Additional information

How to use this resource as an education tool

This resource has been developed to provide service providers with an evidence base on the experiences and needs of LGBT people living with dementia and to promote the development of LGBT inclusive services. It should be used for education in conjunction with more general information about LGBT ageing and aged care. The following table outlines a step by step interactive education program that encompasses general and dementia specific information. It is important that facilitators familiarise themselves with the information in all 6 steps and tailor education to the learning needs of their audience. The duration of education may vary from 2 hours to a full day or series of workshops and can include staff, volunteers or carers. All the resources in the following table are available on the Val's Café website.

Step	Suggested Use
1. Terminology	<ul style="list-style-type: none"> Read <i>Guide Sheet 10 Glossary</i> (see reference 11 below) to familiarise yourself with commonly used terms
2. History and its impacts	<ul style="list-style-type: none"> Watch the <i>Then and Now</i> films (see valscafe.org.au) Read narratives in the <i>My People My Story</i> resource (see valscafe.org.au) Read stories in the <i>No Need to Straighten Up</i> report (see 6 below) Discuss the historical treatment of LGBT Australians and how this might impact on the experiences of LGBT people living with dementia and their intimate partners Discuss how historical perceptions of LGBT people might still influence the attitudes and beliefs of service providers and clients in shared services
3. Legislative reforms	<ul style="list-style-type: none"> Read <i>Guide Sheet 3: Legislative and Other Reforms</i> (see 11 below) to familiarise yourself with reforms Read the <i>National LGBTI Ageing and Aged Care Strategy</i> (see 12 below)
4. Principles of LGBTI inclusive aged care	<ul style="list-style-type: none"> Read the Val's Café <i>Self Assessment and Planning Tool</i> and discuss how your service would rate in an assessment (see valscafe.org.au)
5. Experiences of LGBT people living with dementia and their intimate partners	<ul style="list-style-type: none"> Read the <i>We Are Still Gay ... Case Study Resource</i> (see 4 below). Discuss the case studies using the questions provided. Invite staff and other stakeholders to discuss Watch <i>One Day in the Life of Edie Medew</i> (see ref 5 below) Read the: <i>We are still gay</i> paper (see ref 1 below)
6. Strategies for LGBTI inclusive dementia services	<ul style="list-style-type: none"> Read the key issues and strategies outlined in this resource and discuss how these strategies will be implemented in your service.

References and further reading

The following references are all available from the Val's Café website (see valscafe.org.au)

- Barrett, C; Cramer, P; Lambourne, S & Latham, J (2015). Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia – and their partners. *Australasian Journal on Ageing (LGBTI Ageing Special Edition)*
- Barrett, C; Cramer, P; Lambourne, S & Latham, J (2015). We are still gay ...: the needs of LGBT Australians with dementia. *Australian Journal of Dementia Care*, October/November 4(5) pp 26-30.
- Latham, J & Barrett, C (2015). *Trans ageing and aged care: An evidence based guide to inclusive services*. Australian Research Centre in Sex, Health and Society, La Trobe University.
- Cramer, P; Barrett, C; Lambourne, S & Latham, J (2015). *We are still gay ...* Narrative resource
- Barrett, C. (2015). *One day in the life of Edie Medew: a lesbian with younger onset dementia*. (film)
- Barrett, C; Whyte, C; Leonard, W & Comfort, J. (2013). *No need to straighten up: Discrimination, depression and anxiety in older lesbian, gay, bisexual, transgender and intersex Australians*. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia.
- Fredriksen-Goldsen, K (2011). Resilience and disparities among lesbian, gay, bisexual, and transgender older adults, in R.B. Hudson (ed) *Integrating lesbian, gay, bisexual, and transgender older adults into aging policy and practice*, pp 3-7. Public Policy & Aging Report series. Washington: National Academy on an Aging Society.
- Guasp, A (2011). *Lesbian, gay and bisexual people in later life*. Stonewall: London.
- Beyondblue* (2012) Depression and anxiety in gay, lesbian, bisexual, trans and intersex populations. Position statement.
- Barrett, C; Whyte, C; Comfort, J; Lyons, A & Cramer, P (2014). Social connection, relationships and older lesbian and gay people, *Sexual and Relationship Therapy*, 30(1) (Special Issue), 131-142.
- Cramer, P; Barrett, C; Firth, T & Latham, J (2015). *Aged Care Assessment Service lesbian, gay, bisexual, transgender, and intersex (LGBTI) inclusive guide sheets*. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia.
- Department of Health and Ageing (2012). *National lesbian, gay, bisexual, transgender and intersex (LGBTI) ageing and aged care strategy*. Canberra.

For more information

Val's Café: valscafe.org.au

Alzheimer's Australia: www.fightdementia.org.au

An evidence based guide to inclusive services for lesbian, gay, bisexual and trans people living with dementia

The needs of LGBT Australians living with dementia have not previously been researched. This resource draws on two studies conducted by the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University. The first was an *LGBTI Dementia project* conducted in partnership with Alzheimer's Australia to document the experiences and needs of LGBTI people living with dementia (1,2). The second was a *Trans Ageing and Aged Care project* conducted in collaboration with the Gender Centre NSW, Transgender Victoria and FTM Shed to document trans people's experiences of ageing and aged care, including their experiences of dementia (3). Both studies took place between 2014 – 2015 and involved interviews with 32 lesbian, gay, bisexual and trans (LGBT) participants. No self identified bisexual, trans or intersex people were recruited for the Dementia Project. Interviews were also conducted with six aged care service providers after they contacted the research team to discuss the care needs of trans clients. This resource is part of a LGBT dementia tool kit developed from the research. The tool kit includes early findings from the research (1), a full research report (2), a narrative resource (4) and a film (5).

Overview of the resource

This resource will briefly outline historical and legislative factors influencing the needs of LGBT people living with dementia and present the key issues and strategies arising from the research. It also presents suggestions for using this resource as an education tool to build the basic level of knowledge about LGBT histories, health and wellbeing that is essential to fully appreciate this resource.

BACKGROUND

History, legislative reforms and health and wellbeing provide important context for this resource. A series of Guide Sheets are recommended to provide readers with this context (6) which is also summarised below.

Historical treatment of LGBT Australians

Older LGBT Australians have lived most of their lives aware that disclosing their sexual orientation or transgender identity could result in arrest and imprisonment, psychiatric incarceration and enforced attempted 'cure' treatments (7). Disclosure could also result in the loss of family, friends and employment (7). The effects of these historical experiences are not limited to a particular age cohort. Rather, they continue to shape the way we interact with LGBT people, regardless of their age.

The effects of discrimination

The experience of growing up in homophobic and transphobic societies has contributed to higher rates of depression and anxiety among older LGBT people (7,8,9) and LGBT people more broadly (10). It also resulted in the onus of responsibility being placed on LGBT people to conform to sexuality and gender norms in order to avoid upsetting the status quo (7). This sense of responsibility has persisted across the life span and some LGBT people still believe their sexual orientation or trans gender identity should be hidden to avoid confronting others (1). For some, intimate relationships and friendships with other LGBT people represents the only place they feel safe or able to be themselves (7,11).

Legislative and policy reforms

Recently there have been significant reforms recognising the rights of older LGBT Australians (7). These reforms include the development of a *National LGBTI Ageing and Aged Care Strategy* in 2012 (12). The Strategy describes the Government's commitment to ensuring the needs of older LGBTI people are understood, respected and addressed in Australia's aged care policies, programs and services. It identifies responsive dementia assessment and care as a key action area and makes explicit reference to the importance of ensuring that dementia services are inclusive of and responsive to the needs of LGBTI people (12). The Strategy also highlights the need to "empower older LGBTI people as self-advocates and experts to be consulted about their own ageing and aged care needs and circumstances" (12, p.16). This resource aims to promote the development of LGBTI inclusive dementia services by consulting LGBT people with dementia.

Suggested citation

Barrett, C; Cramer, P; Lambourne, S & Latham, J (2015). *We are still gay ...* An evidence based guide to inclusive services for LGBT people living with dementia. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne Australia.

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Key issues and strategies

In this section of the resource key issues from the interviews are presented alongside strategies to meet the needs of LGBT people living with dementia

Sexual orientation

Being lesbian, gay or bisexual was described as a fundamental aspect of personhood that endured beyond the diagnosis of dementia. The failure to recognise sexual orientation or same sex relationships negatively impacted on the wellbeing of LGBT people living with dementia and their intimate partners. *It is important that service providers recognise the sexual diversity of people living with dementia.*

Transgender identity

Some trans people living with dementia required support to maintain their gender identity and this support was not always provided by family members or service providers. *Gender identity needs to be recognised as a fundamental human right and support provided to enable people living with dementia to maintain their preferred gender identity.*

History and onus of responsibility

Participants reported fears that discrimination still occurred. There was a sense of responsibility to manage disclosure of sexual orientation or gender identity to escape discrimination and also to avoid making others uncomfortable. *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.*

Fear of discrimination

Some LGBT people fear that dementia will make them vulnerable to homophobic and transphobic abuse, particularly from service providers. This resulted in delay or refusal to access services they needed. *Service providers could significantly address the fears of LGBT people living with dementia by demonstrating their commitment to providing LGBT inclusive services.*

The nature of disclosure

The fear of discrimination resulted in some LGBT people hiding their sexuality, transgender identity, body and/or relationships. This in turn resulted in participants not fully disclosing their needs. *Service providers who demonstrate LGBT inclusive practice will communicate to LGBT people living with dementia and their intimate partners, that they are aware of the importance of providing a safe spaces for full disclosure of needs.*

Managing disclosure

Many LGBT people survived historical experiences of discrimination because they learned to determine when and with whom it was safe to disclose their sexual orientation or transgender identity. Managing disclosure in this way required a significant level of cognitive function that diminished with dementia. The fear of inadvertent disclosure was a source of stress for some LGBT people living with dementia and intimate partners. *Service providers who are aware of the fear of inadvertent disclosure can alleviate anxiety by communicating that they are LGBT inclusive.*

Acknowledging intimate relationships

Intimate relationships held particular significance in the lives of LGBT people living with dementia. The relationships provided a protective space against discrimination and a place where diversity was affirmed. Despite this, intimate partners were not always recognised by families of origin or service providers. This was particularly distressing for LGBT people. *It is important that service providers recognise and respect the diversity of intimate relationships.*

Intimate partners as carers

The fear of discrimination in services resulted in LGBT people living with dementia delaying or refusing to access services. Some couples promised to take care of each other at home to avoid services they feared would discriminate. Many didn't have children or families of origin for support. The heavy reliance on intimate partners adversely impacted on carer physical and mental stress. *Service providers need to demonstrate they are LGBT inclusive in order to build the confidence of LGBT people who require support.*

Carer groups

Carer groups were reported to provide a valuable source of support. However, some LGBT carers did not feel welcome in groups where heteronormative assumptions were made about their lives and relationships. *The facilitation of carer support services need to take into account the diversity of carer sexual orientation and gender identity to ensure groups are accessible to all carers.*

Families of origin

Participants who described earlier conflict with their family of origin reported being vulnerable to further abuse as their dementia progressed. The process of working through conflict with family of origin re-traumatised LGBT people living with dementia and their intimate partners who were already experiencing carer stress. *Service providers who understand the historical tensions that occur with some families of origin and the legal rights of LGBT people are well placed to recognise the emotional difficulty of such conflicts and advocate for the rights of the LGBT person living with dementia – particularly those who don't have an intimate partner.*

Social connection

Being socially connected to LGBT communities was reported to enable LGBT people living with dementia and their partners to 'be themselves', 'speak freely' and feel understood. Social connection is linked to improved health and wellbeing and therefore the loss of these social networks was particularly upsetting. *There is a need to educate LGBT communities on the importance of reaching out to support community members living with dementia, particularly those without an intimate partner. There is also an opportunity to inform LGBT people living with dementia about LGBTI specific community visitors schemes (where these exist) and the important support they can provide.*

Grief

The death of an intimate partner who had lived with dementia was described as particularly difficult. Grief was expressed in relation to the loss of companionship, the discrimination and difficulties encountered, the lack of recognition by families of origin and the loss of LGBT community connections. *There is a need to recognise and support intimate partners after the death of their partner. This support is particularly important for those who are socially isolated and others whose experiences and relationships have not been validated.*

Activity programs

Accessing activity groups or events provided important opportunities for LGBT people living with dementia to socialise and provided respite for their partners. However, heteronormativity in these services was described as a barrier to engaging the interest of LGBT people living with dementia. *There is an opportunity to engage with LGBT people living with dementia to ensure activity and event programs are not heteronormative.*

Going it alone

Many participants described the importance of advocacy. Some were skilled self-advocates and others worked hard to advocate for their partner who was living with dementia. There was an awareness that advocacy was required to ensure rights were not violated, and to prevent homophobic or transphobic abuse. In reflecting on this, a number of participants expressed concerns for LGBT people who did not have a partner to advocate on their behalf. *Service providers are well placed to identify LGBT people living with dementia who do not have an advocate or supports. Service providers have a key role to play in ensuring needs are identified and supported and their rights are respected.*

Powers of attorney

Some families of origin and service providers did not recognise the legal rights, authority or expertise of LGBT people's intimate partners. Several participants reported that their application for power of attorney to make decision for their intimate partner, who was living with dementia, was contested by homophobic or transphobic families of origin. While the legal rights of intimate partners were upheld, the challenge and claims made by family of origin caused significant distress for intimate partners at a time when they were under resourced. LGBT people with dementia may benefit from documenting powers of attorney (legal documents describing who can make decisions for them) to ensure their dignity and rights are upheld. Developing and allocating powers of attorney as early as possible may assist in minimising conflict and is particularly important for those 'going it alone' without an intimate partner.

Advance care planning

Some trans people reported having spent their life educating service providers and family members about their gender identity and health care needs and wishes. With dementia the loss of capacity to do this made them vulnerable to transphobic family members and service providers. Documenting future health care wishes in an advance care plan is a useful strategy for all LGBT people, and trans people in particular, to ensure their needs are understood and wishes are respected when they are no longer able to communicate their needs and wishes.