

RESOURCES AND FURTHER INFORMATION

This resource can be used for education in conjunction with general information about LGBTI ageing and aged care. The following table outlines a step-by-step interactive education program. 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 the Aged Care Assessment Service LGBTI Inclusive Guide Sheets (see valscafe.org.au) to familiarise yourself with commonly used terms
2. History and its impacts	<ul style="list-style-type: none"> Watch the Then and Now films (see valscafe.org.au) Read narratives in the My People My Story resource (see valscafe.org.au) Read stories in the No Need to Straighten Up report (see reference list #7) Discuss the historical treatment of LGBTI Australians and how this might impact on LGBTI carers Discuss how historical perceptions of LGBTI people might still influence the attitudes and beliefs of service providers and other carers in carer groups
3. Legislative and other reforms	<ul style="list-style-type: none"> Read the Aged Care Assessment Service LGBTI Inclusive Guide Sheets to familiarise yourself with legislative and other reforms Read the National LGBTI Ageing and Aged Care Strategy (see reference list #13)
4. Principles of LGBTI inclusive aged care	<ul style="list-style-type: none"> Conduct a self-assessment using the Val's Café Self-Assessment and Planning (SAP) Tool (see valscafe.org.au)
5. Key issues and strategies for older carers and the carers of older LGBTI people	<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.
6. The lived experiences of older LGBTI carers and the carers of older LGBTI people	<ul style="list-style-type: none"> Read stories the Narrative report from this project (see valscafe.org.au)

References

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- Cramer, P; Barrett, C; Lambourne, S and Latham, J.R. (2015). We are still gay ... Narrative resource
- Latham, J.R and Barrett, C. (2015). "We're People First" Trans Health and Ageing: An evidence-based guide to inclusive care. Australian Research Centre in Sex, Health and Society, La Trobe University.
- Latham, J & Barrett, C (2015) As We Age. Intersex Ageing and Aged Care: An Evidence-Based Guide. 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
- Barrett, C; Cramer, P (2015). Because we care ... An evidence based resource exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne Australia
- Val's Café Self-Assessment and Planning (SAP) Tool available from: valscafe.org.ua
- Cramer, P; Barrett, C; Latham, JR and Whyte, C. (2015). It is more than sex and clothes: Culturally safe services for older lesbian, gay, bisexual, transgender and intersex people. Australasian Journal on Ageing. 34(S2), p 21-25

An evidence based guide exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people

There are currently 2.7 million unpaid carers in Australia, 39% of whom provide more than 40 hours of care a week (1). This caring comes at a cost to carers – they have poorer wellbeing than the broader community and their wellbeing declines as the hours they spend caring increases (2).

Little is known about older LGBTI carers in Australia. However, we do know that older LGBTI people are more likely to be carers and rely on intimate partners and friend carers (3). This is attributed to the facts that older LGBTI people have limited contact with biological family (4) and they are less likely to have children (5). It has also been attributed to their historical experiences of discrimination – which have contributed to delays accessing formal services due to fear of discrimination (3, 6, 7).

The importance of understanding the experiences and needs of older LGBTI carers and the carers of older LGBTI people has been highlighted in a number of research projects undertaken by Val's Café at the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University. This research has documented the experiences of same sex partners caring for a person with dementia (8, 9, 10), the role of trans carers as advocates (11) and the experiences of an intersex carer (12). However, to date there has been no research exploring the experiences of older LGBTI carers.

This guide draws on research conducted by Val's Cafe in partnership with Carers Australia. The aim of the research was to document the experiences and needs of older LGBTI carers and the carers of older LGBTI people. The research took place in 2015 and gathered data from 54 carers - 49 completed an online survey and 5 participated in in-depth interviews. The Human Research Ethics Committee at La Trobe University approved the research.

Legislative and policy reforms

In recent years there have been significant reforms recognising the rights of older LGBTI Australians (6). These include an amendment to the Aged Care Act (Commonwealth Government of Australia, 1997) to afford older LGBTI people special needs group status and the development of a National LGBTI Ageing and Aged Care Strategy (13). 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 includes specific goals related to the importance of understanding and addressing the needs of carers.

About this resource

This resource has three sections and should be read alongside the narrative resource developed from this project (14). In the following section a summary of the key issues arising from the survey and interviews is presented. The issues are drawn from concurrent research at ARCSHS where the experiences of older LGBTI carers were identified (8, 9, 10, 11, 12). Alongside each issue, strategies are presented. The final section presents a list of resources and suggestions on using this resource.

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Suggested citation Barrett, C; Cramer, P (2015). An extra degree of difficulty. An evidence based guide to the experiences and needs of older LGBTI carers and the carers of older LGBTI people. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne Australia



KEY ISSUES & STRATEGIES

In this section key issues that relate specifically to older LGBTI carers and the carers of older LGBTI people are presented.

Caring for biological family

A number of participants described caring for biological family members who were homophobic. This created additional carer stress – eroding self-esteem and placing pressure on same sex relationships. Participants also reported that heteronormativity in carer support groups meant they had limited opportunities to be supported through these challenges. *Information needs to be provided to LGBTI carers so they understand how to locate LGBTI inclusive supports and to ensure they have sufficient opportunities for respite and debriefing.*

Caring for partners

Several participants reported their intimate partner was reluctant to access aged care services because of the fear of discrimination. In these cases the responsibility for care rested solely on the intimate partner, adversely affecting carer wellbeing. *Service providers need to undertake a self-assessment using the LGBTI SAP Tool (15), implement strategies to provide LGBTI inclusive services and then communicate their inclusivity to LGBTI communities. This will assist older LGBTI carers to navigate safe and inclusive services for both themselves and their partner.*

Social support

Connection with other LGBTI people was described as an important aspect of carer wellbeing. Social networks provided spaces where older LGBTI people could ‘be themselves’ and ‘speak freely’ in a world that was often experienced as homophobic or transphobic. However, carers described how these important networks were difficult to maintain alongside their caring responsibilities and reported feeling socially isolated. *LGBTI communities need to support older LGBTI carers. There is also an opportunity to link older LGBTI carers with LGBTI specific Community Visitors Schemes (CVS) where these exist and ensure that CVS programs make links with mainstream carer groups.*

Grief

Grief was expressed in relation to the loss of companionship the loss of a partner, changes in relationship dynamics, the discrimination and difficulties encountered, the lack of recognition by families of origin and the loss of LGBTI community connections. *There is a need to recognise the layers of grief that may be experienced by older LGBTI carers and to provide access to psychological support. The development of LGBTI specific carer groups and carer counselling could assist in achieving this. Support is also needed following the death of an intimate partner, or friend.*

Carer groups

A significant number of participants reported that heterosexual carers in carer support groups didn’t understand the historical or contemporary issues they encountered. Consequently a number withdrew and requested the development of LGBTI specific carer groups. *There is a need to develop LGBTI specific carers groups. There is also a need to ensure that facilitators of carer groups have the necessary skills and information to ensure LGBTI carers are welcomed by all participants of the group.*

Lack of information targeting LGBTI carer

Several participants expressed frustration at the lack of information specifically for LGBTI carers. *Carer services need to provide LGBTI inclusive services and promote their inclusivity to LGBTI communities and organisations. LGBTI communities also need to promote information about carer supports throughout their networks*

Acknowledging carers

Intimate partners and friends caring for an older LGBTI person described having a unique bond - carers provided safe spaces where diversity was understood and affirmed. However, same sex relationships and LGBTI carers were not always acknowledged by service providers. This created additional stress, particularly where there was conflict with families of origin. *It is important that service providers recognise and respect the important role that older LGBTI carers play. This includes ensuring carers are involved in decisions about care and that documentation is LGBTI inclusive.*

Living in rural and remote areas

Several carers articulated difficulties related to the lack of support services in rural and remote locations, which meant having to uproot themselves from networks where they felt safe as an LGBTI person. *There is a need for services to identify creative ways to support LGBTI carers living in rural and remote locations. LGBTI communities in these locations need to provide support for LGBTI carers*

Staff values and beliefs

LGBTI carers reported being adversely impacted by service provider’s prejudicial values and beliefs about LGBTI people. This led to barriers to services access, compromised quality of care, or refusal of services.

A number of carers also reported some service providers believed they were exempt from providing services to LGBTI people because they had a culturally diverse workforce or were a faith based service. In addition, many more participants expressed fear that faith based services would discriminate. These experiences created additional carer stress and exacerbated carers fears of discrimination. *Further education for the service sector needs to occur to ensure staff understand the impact that their values and beliefs have on the delivery of LGBTI inclusive and culturally safe services (16). Organisations need to provide clear leadership to staff and other service users to communicate their commitment to LGBTI inclusive service delivery. Staff education must include information that there are no exemptions from LGBTI inclusive service provision and that it is unlawful to refuse services on the basis of sexual orientation, gender identity, or intersex status.*

Respectful dialogue about workforce diversity and LGBTI inclusive practice must occur. The cultural diversity of the aged care workforce and the provision of services by faith based organisations ought not be seen as obstacles to the provision of LGBTI inclusive services.

Service responses to LGBTI staff

A number of carers described concerns about LGBTI staff experiencing discrimination in aged care services. Therefore this was seen as evidence that services would not welcome LGBTI clients and contributed to further reluctance to access services. *Service providers need to understand that the provision of LGBTI inclusive services requires organisational leadership to ensure LGBTI staff are recognised and valued. Strategies to welcome LGBTI staff could be promoted to demonstrate LGBTI inclusive services for carers.*

A message of welcome

A number of participants reported the failure of services to send a message of welcome to LGBTI people. Several reported that information about local support services lacked LGBTI inclusive language and imagery. This included the language used at intake and assessment. Carers reported feeling reluctant to access services unless there was a message of welcome. *Service providers need to ensure organisational information communicates a message of welcome to LGBTI people. Government mandated templates and documentation need to be amended to ensure they are LGBTI inclusive. Service providers should identify creative ways of sending a message of welcome. These initiatives will assist in ensuring carers feel welcomed and safe accessing these services.*

Service development: extra degree of difficulty

While most carers experience challenges, the LGBTI participants in this research reported experiencing an extra degree of difficulty. This included caring for homophobic family members and the fear of discrimination by services. Indeed 43% of carers who completed the survey experienced discrimination in relation to their sexual orientation, gender identity or intersex status as an older LGBTI carer or the carer of an older LGBTI person. Not surprisingly 28% delayed accessing services because of the fear of discrimination. *The unique challenges experienced by older LGBTI carers need to be understood and considered in the development of LGBTI inclusive services to ensure equitable access for older LGBTI carers.*