

LGBTI fact sheet 11 - Care relationships

The importance of care relationships

Older LGBTI adults are at greater risk of isolation than their counterparts. Gay, lesbian and bisexual people are less likely than heterosexual people to be living with a partner (1-3).

- LGBTI peoples may have been rejected by their biological families many years earlier and are less likely to have children and/or significant others.

Family of origin & family of choice

- LGBTI peoples may refer to their 'family of origin' or biological family which may or may not be a part of their everyday lives, and their 'family of choice' which may include a same-sex partner, friends, a previous partner and/or members of their community (4, 5).
- There are many caring relationships involving older LGBTI peoples, including:
 - LGBTI peoples providing care for their partner (living together or separately),
 - LGBTI peoples providing care for heterosexual parents or other relatives,
 - LGBTI or heterosexual adult children providing care for lesbian or gay parents or co-parents,
 - Heterosexual people providing care for an ex-partner, friend or parent who has 'come out' as LGBTI later in life (6).
- Older LGBTI peoples may have been rejected by, or have rejected, their families of origin (7, 8). For some, the rejection by their family may have happened when

they were much younger and may have occurred in response to their 'coming out'. Others may have 'come out' or been 'outed' by others later in life and then been rejected by their adult children (6).

- Support from family of choice and their connection with a partner is often paramount for LGBTI peoples with dementia, particularly where they do not have the support of their biological families (9-15). However the expression of support from a loving partner through touch and affection may be lost to the person with dementia when reactions from others around them are negative (3).
- It is important to use terms like 'family' inclusively. LGBTI elders' designated family of choice must be treated as equal in importance to biological family members and given the opportunity to be included in care planning (15, 16).

***Note:** It is particularly important for LGBTI peoples to put advance care plans in place prior to the point when the severity of their dementia makes this impossible.

- Same sex partners and carers are vulnerable to being marginalised, discredited and ignored if their role in decision-making is not documented or appropriately authorised as their legal next of kin (17, 18).
- Advance care planning will help the person with dementia's family of choice, biological family, healthcare team and aged care providers to make

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appropriate decisions on their behalf (19).

***Note:** An Advance Care Plan or Advance Care Directive enables a person to document their healthcare wishes, have their values respected and ensure they receive the healthcare they choose should they be unable to instruct medical professionals at that time.

- Where this is not in place and the biological family does not support the sexuality, intersex status or gender identity of a person who is L, G, B, T or I, dementia can mean they are vulnerable to the decisions of family members who do not value who they are (11, 18).
- These experiences may prompt behavioural and psychological symptoms of dementia (BPSD) such as depression, anxiety, delusions, agitation or aggression.

LGBTI carers' experiences

- LGBTI peoples with dementia may become increasingly reliant on their partner for care when fear of discrimination, around disclosure of their sexual orientation, gender identity or intersex status delays contact with service providers (4, 11, 20-22).
- Carers of people with dementia frequently experience issues such as stress and grief as well as poorer health and wellbeing as a consequence of the physical and emotional demands of their role. LGBTI carers may face additional issues:
 - Increased isolation due to fear of discrimination or being outed by service providers
 - Lack of family support and respite increasing the person with dementia's dependence on the carer
 - Reluctance to access support or health services due to fear of discrimination; subsequent delays in addressing their needs may compound health issues and increase cost implications
 - Lack of relevant carer support to enable discussion of the specific challenges of their caring role
 - Delays in accessing services increases the person with dementia's vulnerability to premature admission to permanent residential care due to carer burnout and illness (21, 23).
- Discrimination at various levels of service provision can lead to barriers for many LGBTI carers exacerbating stress and negatively impacting on their quality of life and that of the person with dementia (24, 25).
- Additionally, carers may take on the additional responsibility of ensuring the safety of the person with dementia, attempting to protect them from discrimination and heterosexism in the context of aged care (25).
- LGBTI specific carer support groups are lacking (26). Carer support groups targeting the wider community may unintentionally reinforce heteronormative perspectives and assumptions where members are in heterosexual relationships or of binary gender only.
- This may discourage LGBTI carers from disclosing and sharing honestly and in

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turn, they may not receive much-needed support (11).

- Taking on a caring role may present opportunities to revisit and re-evaluate previously difficult and damaged or damaging relationships with members of the person with dementia's biological family.
- The quality of a care relationship is often shaped by the person with dementia and the carer's previous acceptance of each other's sexual orientation, gender identity and/or intersex status (10). Examples include adult children having difficulty accepting their parent's decision to transition later in life or a person with dementia who has never accepted their child's LGBTI identity where dementia requires them to take on a caring role.
- A person with dementia may forget at times that their family carer, e.g. son or daughter is a person who is L, G, B, T or I which may prompt a change in their behaviour and response to the carer.

Loss of a partner

- The death or incapacity of a partner may prompt the move of a person with dementia who is L, G, B, T or I into residential care or to live with their biological family who may not acknowledge or respect the relationship.
- 'Disenfranchised grief' occurs when a person is grieving but they cannot talk about their pain because those around them do not consider it valid.
- LGBTI peoples can experience disenfranchised grief when they cannot openly acknowledge the loss of a partner

because their relationship is not recognised as legitimate.

- Where a relationship is not socially endorsed or a death is not publicly mourned the surviving partner is at risk of complicated grief (27-34).
- Where those in a long term LGBTI relationship lose their partner but have never felt safe to identify themselves as such, they may have nowhere to turn to for support.
- They may not feel part of the LGBTI community because of their lifelong secret and yet they may also lack support from others outside the LGBTI community (22).

***Note:** Unresolved or complicated grief in dementia may prompt intensified reactions to the loss and consequent BPSD such as depression, anxiety or aggression.

- Some LGBTI peoples may have experienced invalidation of their relationships throughout the lives in that their relationships may not have been accepted legally or socially.
- This can further complicate their grief and the bereavement experience (27), increasing their vulnerability to BPSD.

Example scenario

Apart from his closest, long term friends, Ian had more or less lived 'in the closet' throughout his working life. He felt that he would risk losing his career and his network of work friends if he were to be 'out' about his bisexuality. For some years he had been looking forward to retirement when he felt

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he could finally be open about who he was. After 'coming out' when he retired at age 60, Ian was finally enjoying life as part of the LGBTI community. Sadly, he was diagnosed with young onset dementia a few years later. He lost the capacity to make decisions and care for himself quite quickly.

Although they had little contact as adults, Ian's sister Debbie was his only next of kin. Ian had not previously given Power of Attorney to any of his close friends or members of his 'family of choice'.

Debbie had never accepted or supported her brother's sexual identity, however she was determined to take control of his care. Ian was placed in a care facility close to Debbie but far from his friends and his LGBTI support network. Debbie also insisted to the nursing home staff that should Ian talk about his sexual identity staff must not acknowledge it, claiming that this thinking is due to his confusion and advancing dementia. Ian is now isolated from the people he was closest to and presents as depressed.

Discussion points

- Consider the steps your organisation could take to allow Ian to have contact with his close friends and support from the LGBTI community.
- How could Debbie be supported to respect who Ian is even if she doesn't understand his sexual identity?
- Consider the steps individual staff members can take such as seeking further education around the rights of residents who identify as L, G, B, T or I and examining their individual approach to Ian to help him feel less isolated.

References

1. Australian Bureau of Statistics. 4326.0 - National Survey of Mental Health and Wellbeing; Summary of Results. Canberra; 2007.
2. Alzheimer's Society UK. Supporting lesbian, gay and bisexual people with dementia. London: Alzheimer's Society UK; 2013.
3. GLBTI Retirement Association Incorporated (GRAI). The care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD). Perth Australia: GLBTI Retirement Association Incorporated 2013.
4. Barrett C, Whyte C, Comfort J, Lyons A, Crameri P. Social connection, relationships and older lesbian and gay people. *Sexual and Relationship Therapy*. 2014;30(1):131-42.
5. Jones RL, Almack K, Scicluna R. Older bisexual people: Implications for social work from the 'Looking Both Ways' study. *Journal of gerontological social work*. 2018;61(3):334-47.
6. Birch H. Dementia, Lesbians and Gay Men: Alzheimer's Australia Paper 15. Vic, Australia: Alzheimer's Australia; 2009 October 2009.
7. The Gender Centre Inc. Inquiry into elder abuse in New South Wales. Sydney: The Gender Centre Inc; 2015.
8. Grant J, Mottet L, Tanis J, Harrison J, Herman J, Keisling M. Injustice at every turn: A report of the National Transgender Discrimination Survey. Washington DC, US: National Centre for Transgender Equality and National Gay and Lesbian Task Force; 2011.
9. Weeks J, Heaphy B, Donovan C. Same-Sex Intimacies: Families of Choice and Other Life Experiments , . London: Routledge; 2001.
10. Price E. Caring for mum and dad: Lesbian women negotiating family and navigating care. *The British Journal of Social Work*. 2011;41(7):1288-303.
11. Barrett C, Crameri P, Lambourne S, Latham J. 'We are still gay...': the needs of LGBT Australians with dementia. *Australian Journal of Dementia Care*. 2015;4(5):26-30.
12. Fredriksen KI. Family Caregiving Responsibilities among Lesbians and Gay Men. *Social Work*. 1999;44(2):142-55.
13. Peel E, Taylor H, Harding R. Sociolegal and practice implications of caring for LGBT people with dementia. *Nursing older people*. 2016;28(10):26-30.
14. Jones S, Willis P. Are you delivering trans positive care? *Quality in Ageing and Older Adults*. 2016;17(1):50-9.

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15. McParland J, Camic P. Psychosocial factors and ageing in older lesbian, gay and bisexual people: a systematic review of the literature. *Journal of clinical nursing*. 2016;25(23-24):3415-37.
16. Gay and Lesbian Health Victoria (GLHV). A framework for LGBTI-inclusivity in service risk-management. Victoria, Australia: La Trobe University; 2018.
17. ACON. Ageing: Health Outcome Strategy 2017-2021. Sydney, Australia: ACON; 2017.
18. COTA Victoria, Transgender Victoria, Dr Sue Malta National Ageing Research Institute (NARI). Safeguarding the End of the Rainbow: A guide to help LGBTI people to plan an end of life of their choice. . In: Victoria C, editor. Melbourne, Victoria Australia: COTA Victoria; 2018.
19. Australian Government Department of Health. LGBTI Advance Care Planning Factsheet. Canberra, Australia: Australian Government; 2017 April 2017.
20. Barrett C, Cramer P, Lambourne S, Latham JR, Whyte C. Understanding the experiences and needs of lesbian, gay, bisexual and trans Australians living with dementia, and their partners. *Australasian Journal on Ageing*. 2015;34(Suppl 2):34-8.
21. Harrison J. Consultation on protection from discrimination on the basis of sexual orientation and sex and/or gender identity. SA, Australia; 2010.
22. Stein GL, Beckerman NL, Sherman PA. Lesbian and gay elders and long-term care: identifying the unique psychosocial perspectives and challenges. *Journal of gerontological social work*. 2010;53(5):421-35.
23. Barrett C, Whyte C, Cramer P. Creating gay, lesbian, bisexual, transgender and intersex (GLBTI) inclusive home and community care (HACC) services: The HACC pack. Melbourne, Australia: Val's Café and Municipal Association of Victoria; 2014.
24. Coon DW. Exploring Interventions for LGBT Caregivers. *Journal of Gay & Lesbian Social Services*. 2007;18(3-4):109-28.
25. McParland J, Camic P. How do lesbian and gay people experience dementia? *Dementia*. 2016;1471301216648471.
26. Peel E, McDaid S. "Over the Rainbow" Lesbian, Gay, Bisexual and Trans People and Dementia. Project Summary Report. Worcester UK: Institute of Health and Society, University of Worcester; 2015.
27. Cacciatore J, Raffo Z. An Exploration of Lesbian Maternal Bereavement. *Social Work*. 2011;56(2):169-77.
28. Doka K. Disenfranchised Grief. In: Doka KJ, editor. *Living with Grief: Loss in Later Life*. Washington, D.C. : The Hospice Foundation of America; 2002. p. 159-68.
29. Hughes AK, Waters P, Herrick CD, Pelon S. Notes from the field: Developing a support group for older lesbian and gay community members who have lost a partner. *LGBT Health*. 2014;1(4):323-6.
30. Fenge L-A. Developing understanding of same-sex partner bereavement for older lesbian and gay people: Implications for social work practice. *Journal of gerontological social work*. 2014;57(2-4):288-304.
31. Fenge L-A, Fannin A. Sexuality and bereavement: Implications for practice with older lesbians and gay men. *Practice: Social Work in Action*. 2009;21(1):35-46.
32. Attrell R. Death and intimacy issues in the LGBT community: A gay perspective. In: DeFord B, Gilbert R, editors. *Living, loving and loss: The interplay of intimacy, sexuality and grief*. Amityville, NY, USA: Baywood Publishing Co; 2013. p. 21-42.
33. McNutt B, Yakushko O. Disenfranchised grief among lesbian and gay bereaved individuals. *Journal of LGBT Issues in Counseling*. 2013;7(1):87-116.
34. Cramer P, Barrett C, Lambourne S, Latham J. We are still gay: An evidence based resource exploring the experiences and needs of lesbian, gay, bisexual and trans people living with dementia. Melbourne Australia: Australian Research Centre in Sex, Health and Society, La Trobe University; 2015.

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See *Fact sheet 1 – Overview* for details.