

National LGBTI Health Alliance

lesbian, gay, bisexual, transgender, intersex and other
sexuality, sex and gender diverse people and communities
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Committee Secretary
Senate Standing Committee on Community Affairs
PO Box 6100
Parliament House
Canberra ACT 2600
Australia

Dear Committee Secretary

RE: Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD)

The National LGBTI Health Alliance is pleased to make a submission to the Senate Committee Inquiry into the Care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD).

About the National LGBTI Health Alliance

The Alliance is the national peak health organisation for a range of organisations and individuals from across Australia that work together to improve the health and wellbeing of lesbian, gay, bisexual, transgender, and intersex people and other sexuality and gender diverse people (LGBTI). We support measures which contribute to improved health and wellbeing for LGBTI Australians.

Formed in 2007, the Alliance includes the major providers of services for LGBTI people in Australia, with Members drawn from each State and Territory. The Alliance provides a representative national voice to: develop policy and to support LGBTI health issues; seek increased commitment to services for LGBTI people; develop the capacities of LGBTI organisations; and support evidence-based decision-making through improved data collection covering sexuality, sex and gender identity.

Needs of LGBTI Australians living with dementia and BPSD

There are benefits to society that can be made by recognising the needs of LGBTI people, including improved health and wellbeing outcomes and the increased ability of LGBTI people to participate in and contribute to our families, schools, workplaces, communities and services. We are pleased that some dementia care settings have adopted LGBTI-inclusive policies and made an effort to welcome LGBTI people. However, welcoming attitudes and good intentions are not sufficient to cover LGBTI people's dementia-related needs. Researchers have documented the harm to LGBTI people's health and wellbeing, when dementia-related care and management are not adequately informed by LGBTI-specific practical knowledge and skills (Cronin, Ward, Pugh, King and Price, 2011; Jackson, Johnson and Roberts, 2008; Price, 2008; Ward, Vass, Aggarwal, Garfield and Cybyk, 2005).



Researchers in this field have recommended the inclusion of LGBTI-specific content in health and social care curricula (Benbow and Beeston, 2012) and increased consultation with LGBTI people living with dementia and BPSD and their partners and families. When combined with LGBTI-specific policies that are clear and consistently applied, such curricula can ensure that appropriate responses to LGBTI people and their partners and families will be treated as a professional duty of care rather than as a matter of personal choice by individual staff (Benbow and Beeston, 2012; Ward et al., 2005). In Australia, a number of these issues have been discussed comprehensively in the 2008 research paper [*Dementia, Lesbians and Gay Men*](#), which was commissioned by Alzheimer's Australia. Further research is needed regarding the needs of intersex, trans and gender diverse people living with dementia and BPSD and their partners and families. The Gender Centre in NSW includes some of the specific needs of trans people living with dementia in their training curricula.

In addition to sharing similar needs and challenges to those of other Australians living with dementia and BPSD, younger and older LGBTI Australians dealing with dementia-related concerns have a variety of unique challenges and needs related to their care and management. These needs include, but are not limited to:

- **Protection for and respectful treatment of LGBTI people's relationships and families in the care and management of dementia and BPSD.** LGBTI people have reported experiences of their partners not being consulted about care decisions, even when they have provided powers of attorney, living wills and other documents that are intended to safeguard the rights of people's designated partners. Some LGBTI people have reported that their relationships were not addressed because their partners were assumed to be their biological siblings. Long-term same-gender partners have reported being dismissed by care staff as merely friends. Some LGBTI people have reported that everyday displays of physical affection in the presence of care staff have been treated as signs of dementia-related symptoms or used to restrict people's contact with their partners. When partners experience memory loss or difficulty with behavioural regulation, attitudes and behaviour of care staff can affect people's health outcomes. Adequate support and respect for the partners of LGBTI people who experience dementia and BPSD are needed to minimise the adverse impact on LGBTI people's relationships and families.
- **Policies that allow respect for LGBTI people's relationships, gender identities and intersex status without requiring them to identify openly as LGBTI.** Some people may not feel safe identifying as LGBTI in care settings or with care providers. Some people may not identify with sexual orientation labels, yet still require that their same-gender relationships receive adequate protection and support for dealing with aspects of dementia in themselves or their partners. Specific forms of protection and support may also be needed by intersex and trans people who identify simply as women or men.
- **Clear guidelines and policies for staff regarding how to respect the health and privacy needs of intersex people, trans people and gender diverse people with dementia.** This includes toileting, dressing and personal care. This also includes trans-specific health care needs. For example, trans women living with dementia and BPSD will require daily vaginal dilation, if they have had vaginoplasty. These women will need safe and well-trained care staff to preserve their vaginal health and guard against the potential for sexual abuse to occur during intimate care.



Suggestions for improving care and management

Based on these and other concerns of LGBTI people living with dementia and BPSD and their partners and families, we suggest that providers of their care and management:

- Engage in ongoing consultation with LGBTI organisations such as the National LGBTI Health Alliance and our Member Organisations to ensure that our specific expertise on the needs of these populations can contribute to improved health and wellbeing for these LGBTI people and their partners and families.
- Provide training to all staff on the specific needs of each LGBTI population. This training should specify the need for such training to contain separate components that address the distinct care and management needs of each population included within LGBTI.
- Use LGBTI-inclusive language in intake meetings, service descriptions, care forms, databases, informational materials, policy documents and in other written or verbal interactions. This includes using people's preferred terms to describe their relationships, their genders and their bodies. The Alliance wishes to refer the Committee to our [Inclusive Language Guide](#) on how to use language respectfully when interacting with intersex people, trans people and gender diverse people in a variety of contexts.
- Consider LGBTI people's specific needs, when addressing the issue of access to appropriate respite care. This includes the need for referrals to LGBTI-specific visitors and support services.
- Screen third party providers for LGBTI-inclusion and awareness prior to making referrals to respite care or other organisations, and include specific details of how LGBTI-related needs will be addressed in individual care and management plans as well as in organisational policies.
- Establish policies to protect LGBTI people from inappropriate use of physical and chemical restraints to restrict or punish the expression of their sexual orientation, gender identity or intersex status.
- Provide a clear, confidential pathway for Australians living with dementia and BPSD, their partners and their families to note their LGBTI-related concerns without being 'outed' to all care staff against their wishes.
- Consider the sensitive issues involved when LGBTI people require home-based dementia care and the need for community consultation to determine how best to address these needs.

Some younger LGBTI Australians living with dementia and BPSD experience HIV/AIDS-related forms of dementia and related neurocognitive symptoms . We direct the Committee to the [ACON submission](#) to NSW Health on the Draft NSW Dementia Services Framework 2010-2015. This document addresses some important LGBTI-specific and HIV/AIDS-specific concerns with national relevance for dementia services.

We thank you for taking the time to consider this submission. Feel free to contact the Alliance's Health Policy Officer, Gávi Ansara if you would like to discuss any of the above matters with him.

Yours sincerely

Warren Talbot
GENERAL MANAGER



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