



Mr. Ian Holland, Secretary
Standing Committee on Community Affairs
References Committee
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Parliament House
Canberra ACT 2600
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24 April 2013

RE: Inquiry into the care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia

Dear Mr. Holland:

The GLBTI Retirement Association Inc. (GRAI) appreciates this invitation by the Community Affairs Reference Committee to provide a written submission to the above inquiry, and includes our brief response here.

As concerned Australians, as advocates for our GLBTI¹ elders, and as individuals, couples and family members affected by dementia, we welcome this inquiry on this critically important topic. This inquiry is, we know, part of a broad national dialogue on the complex clinical, legal and ethical issues care of persons with dementia and behavioural and psychiatric symptoms of dementia (BPSD) bring to the fore.

GRAI is a Western Australian not-for-profit, community based organisation. We aim to identify and address the needs of older people of diverse sexualities and gender identities and work to create an inclusive mature age environment to support a good quality of life for GLBTI elders. Nationally, GRAI is the only organisation focusing exclusively on the needs of GLBTI elders.

¹ GLBTI (gay, lesbian, bisexual, transgendered, transsexual and intersex) and LGBTI (lesbian, gay, bisexual, trans, intersex), are used throughout this document. There is much debate on terminology for this group and other terms are also used, including: sexual minority groups, and sexual and gender diverse. GLBTI/LGBTI are used here as a general term to include people who are not exclusively heterosexual in identity, attraction and/or behaviour.

A growing body of research both in Australia and internationally has demonstrated that older LGBTI people have unique and specific needs. If appropriate quality care is to be provided, then all service providers must be cognisant of these needs. As a contribution to the literature in 2010 GRAI published a report raising concerns about the preparedness of aged care service providers in Western Australia to work effectively with older LGBTI adults (*We Don't Have Any of Those People Here: Retirement accommodation and aged care issues for non-heterosexual populations*²), as well as the accompanying *Best Practice Guidelines: Accommodating older gay, lesbian, bisexual, trans and intersex (GLBTI) people*, to address these concerns.

The recognition of LGBTI special needs was demonstrated in the work undertaken by the Department of Health and Ageing as part of the Living Longer Living Better Aged Care Reform Agenda³. In 2012, GRAI joined efforts at the Commonwealth level to increase full inclusion of LGBTI older adults in aged care services, having two representatives on the Commonwealth Department of Health and Ageing's Steering Committee to assist in the development of the now-completed *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*⁴.

LGBTI individuals are among the growing numbers of Australians living with BPSD and dementia. Some members of the Board of GRAI work directly with persons with dementia and BPSD, and all of us are aware that increased attention and funding is needed for research, clinical training, and program development. While many individuals with dementia and BPSD are older, we are aware too of the increasing number of persons with dementia and BPSD who in their 50s and 60s. The care of these often physically fit but cognitively impaired individuals—who may not fit usual expectations of persons with dementia—pose particular challenges for care providers. Funding and planning need to take the needs of these individuals into account, as well as the needs of the partners, friends and family caring for them.

Several decades ago, the HIV epidemic led to changes in ethical guidelines for clinical trials, and to improved understandings of need to involve those affected by health conditions into all levels of research and planning. Today, the growing numbers of persons living with dementia challenge us to develop clearer, more sophisticated and replicable models of “patient-centred care”. Multidisciplinary clinical teams working with people with dementia and BPSD work continually to understand and anticipate the needs of their often communication-impaired clients. They seek to minimise discomfort and distress, physical and emotional pain, and to compensate for the losses in human connectedness that can accompany prolonged, and even permanent, residential placements.

Such quality care can be staff-intensive to provide, and GRAI supports wholeheartedly increased Commonwealth planned approaches to adequately fund the development and delivery of appropriate resources to ensure comprehensive training and staff programs for working with persons with dementia and BPSD. Such training must include appropriate coverage of LGBTI issues to ensure that sensitive and appropriate care is delivered to this group.

² GRAI and Curtin Health Innovation Research Institute, 2010, *We don't have any of those people here*, Curtin University, Bentley, WA.

³ Commonwealth of Australia. (2012). *Living Longer. Living Better Aged Care Reform package*. Canberra.

⁴ Department of Health and Ageing. (2012). *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*. Canberra, Commonwealth of Australia.

The ongoing loss of clinical skills and expertise in such programs due to high staff turnover takes a toll on people living with dementia, their families and other staff; and hopefully this could be minimised through increases in pay, continuing professional development, and seniority career pathways to promote retention. GRAI is also aware of the grossly inadequate numbers of long-term care facility beds to accommodate persons with BPSD, requiring patients at times to remain unnecessarily long in acute mental health hospital beds.

All of these are complex systemic issues, which we know this inquiry will be attempting to address.

Within these broader concerns, GRAI hopes that the inquiry will also consider the particular issues and concerns of persons of diverse sexuality, gender and sex who are impacted by dementia and BPSD—whether as patients, partners and spouses, family members, friends or clinical care staff. The Department of Health and Ageing's *National LGBTI Ageing and Aged Care Strategy* includes principles and specific goals to increase inclusion and improve care of older LGBTI adults—and nowhere would sensitivity to these issues be more helpful than in the care of persons with dementia and BPSD.

The *National Strategy's* principles and goals include:

- Availability of LGBTI-inclusive care services;
- Provided by a workforce knowledgeable of LGBTI issues;
- Backed by research that is inclusive of LGBTI people and concerns;
- With equitable access to quality and inclusive services for LGBTI older adults;
- That resources be made available to support proactively the addressing of the needs of LGBTI older adults; and that
- The LGBTI sector be involved in the planning, delivery and evaluation of aged care policies, programs and services.

Heather Birch, in the 2009 Alzheimer's Association report *Dementia, Lesbians and Gay Men*⁵, outlined some of the ways LGBTI people may be more specifically impacted by dementia and BPSD—those with dementia and their partners, and also younger lesbians and gay men who may be caring for a heterosexual family member living with dementia. Her report raises important concerns still relevant after several years.

As examples of these issues, higher numbers of LGBTI older adults than mainstream peers live alone, and more are single in older adulthood. This could result in some cases in later detection and treatment of dementia, while lack of in-home supports could also result in earlier residential care placement. Dementia may cause a reduction in an individual's ability to conceal and self-censor behaviour, and the ability to make informed disclosures—all of which may place LGBTI individuals at risk should they act outside what are considered norms for public same-sex affection, or outside traditional gender norms.

LGBTI people and their partners may be particularly impacted by the loss of privacy that accompanies residential care placement, with abilities to support an impaired

⁵ Birch, H. (2009). *Dementia, Lesbians and Gay Men*. Alzheimer's Australia. Melbourne, Alzheimer's Australia.

partner through touch and physical affection decreased when partners fear negative reactions from staff or other residents.

LGBTI-inclusive dementia care services can support staff in addressing many of these concerns. A workforce well-educated in GLBTI cultural awareness, supported by organisational policies which promote a GLBTI-positive environment, will be able to ensure GLBTI people are safe from overt and covert discrimination and discrimination. The awareness of individuals' distinct backgrounds and needs that they encourage are the general ones that govern all good person-centred care. For this reason, such inclusive services need not add a burden to already-taxed dementia and BPSD staff—because they are fully consistent with existing best practices. And all patients and staff can benefit from awareness in the areas of sexuality and gender diversity, with the ability to deliver individualised and effective care being strengthened.

Recent times have seen significant changes in societal attitudes towards diverse sexuality and gender expression. It is hoped that these more enlightened attitudes are translated into practice in all care and service sectors, and that legal reforms and appropriate training can provide the necessary urgent changes to support their GLBTI clientele.

We support this inquiry in its important work, and hope that the public consultation assists in strengthening services for persons with dementia and BPSD and specifically to ensure that LGBTI focused care and services are available. We hope application of the principles and goals outlined in the *LGBTI National Aged Care Strategy* will provide an important dimension to these efforts.

If you would like clarification on any of the above point, do not hesitate to contact either Dr Dan Parker or Dr Jude Comfort through info@grai.org.au

Yours sincerely,

Dr Daniel Parker
Board Member

Dr Jude Comfort
Chair