

# LGBTI fact sheet 1 - Overview

## Background to the project

The BPSD team at the Dementia Centre for Research Collaboration (DCRC)\* at UNSW Sydney (University of NSW) has developed evidence and practice-based resources based on the document *Behaviour Management, A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia (BPSD Guide, 1)*.

- The BPSD Guide was developed to provide guidance for clinicians working with the Dementia Behaviour Management Advisory Services (DBMAS) in their role of assisting residential aged care facility staff, community care staff and family members caring for people with dementia, who present with behavioural and psychological symptoms of dementia (BPSD).
- The document incorporates a comprehensive overview of BPSD management principles with practical strategies, interventions and example scenarios.
- Demand for the BPSD Guide beyond DBMAS led to the development of a suite of associated resources available at <https://cheba.unsw.edu.au/ClinicalCare>.
- The BPSD Guide incorporates additional considerations for those with dementia from Aboriginal and Torres Strait Islander communities and Culturally and

(\*Now merged with the Centre for Healthy Brain Ageing (CHeBA) at UNSW Sydney)

Linguistically Diverse (CALD) backgrounds.

- At this time additional considerations to support LGBTI peoples who present with BPSD are not included. This resource seeks to address that gap.

### Resource overview

- These fact sheets have been developed to inform those providing care to people with dementia of the additional considerations required when caring for lesbian, gay, bisexual, transgender and intersex (LGBTI) peoples who present with BPSD.
- Terms such as changed behaviours, responsive behaviours, behaviours of concern, behavioural and psychological changes in dementia and others are also used to describe BPSD (2).
- These terms aim to raise awareness of a person with dementia's behavioural expression or psychological response to a situation which requires intervention. Recognising and understanding the multiple underlying factors that are potentially contributing to the BPSD will help to identify the most appropriate intervention.

**\*Note:** Being a person who is L, G, B, T or I is NOT a choice, a mental or physical illness or related to inappropriate behaviour.

- BPSD are not linked to LGBTI peoples' identities. BPSD are influenced by a person with dementia's history, personal experiences, those around them and their living environment.

# 1 - Overview

- The target audience for this resource is care staff and health professionals working in all aged care and related settings, including residential, community and acute services.
- While awareness of the special needs of people who identify as LGBTI living with dementia in aged care is increasing (3, 4), information on additional considerations for managing BPSD in LGBTI peoples is currently lacking (5, 6).
- This resource is based on a comprehensive search of the academic and grey literature relevant to LGBTI peoples with dementia and consultation with consumers, experts and those experienced in providing services to LGBTI people with dementia.
- The additional considerations outlined in this set of twenty fact sheets are aligned with the evidence and practice-based principles included in the *BPSD Guide* (1) and associated resources.
- This resource is not about changing personal beliefs. It is about professional practices in the workplace and ensuring that LGBTI peoples with dementia receive inclusive, person-centred care.
- While it is important to treat all clients, residents and patients with respect, 'treating everyone the same' ignores the challenges faced by LGBTI people and the fact that to achieve equality in services we need to recognise and respond to these unique differences (7-9).
- Person-centred LGBTI inclusive care in all community, residential and acute contexts requires an awareness that each person has a different lived experience and individual needs (10, 11).

**\*Note:** The aim of this resource is to provide background information on the lived experiences of LGBTI peoples which can influence the presentation of BPSD and the additional considerations relevant to their care. It does not aim to provide comprehensive information on the principles of supporting those who present with BPSD.

- We recommend readers also access the suite of resources previously developed by DCRC and Dementia training Australia (DTA) for clinicians, direct care staff, families and care partners to assist in supporting those who present with BPSD:  
<https://cheba.unsw.edu.au/ClinicalCare> and  
<https://www.dementiatrainingaustralia.com.au/>.

## Key learning objectives

After reading this resource users will be able to:

1. recognise the factors that contribute to the specific needs of LGBTI peoples with dementia and how these relate to the principles of supporting those who present with BPSD
2. outline the additional considerations required when providing care to LGBTI peoples who present with BPSD as well as those providing support
3. identify the impact of the following on the presentation and management of BPSD:
  - personal history and lived experience
  - physical and mental health
  - care environment, including staff, visitors and other clients, patients or residents

# 1 - Overview

- care relationships including the person with dementia's family of choice and biological family
- communication and interaction with others

4. recognise the challenges and enablers to implementing LGBTI inclusive care practices in their workplace
5. identify culturally appropriate strategies they can employ to support LGBTI inclusive care practices.

## Disclaimer

This resource is provided for general information only and does not claim to reflect all considerations.

### The Dementia Centre for Research Collaboration (DCRC)

- The Dementia Centre for Research Collaboration (DCRC) at UNSW Sydney does not seek to provide professional or medical advice on any specific matter. As with all guidelines, recommendations may not be appropriate for use in all circumstances. Care providers should also consult guidelines provided to them by deploying or responsible agencies.
- This resource incorporates information from the most recent literature and other sources. Every effort has been made to ensure the accuracy and reliability of the information in these fact sheets at the time of publication.
- Links to Internet Sites and resources are also identified; however these represent only a selection of those available. Links

- to other Internet Sites that are not under the control of the DCRC are provided for information purposes only.
- Care has been taken in providing these links as suitable reference resources. However, due to the changing nature of Internet content, it is the responsibility of users to make their own investigations, decisions and enquiries about any information retrieved from other Internet sites. The provision and inclusion of these links do not imply any endorsement, non-endorsement, support or commercial gain by UNSW Sydney.

## Responsibility

- While this resource was prepared after an extensive review of the literature, review by an expert advisory committee and broad consultation, the responsibility for clinical decisions is borne by the clinician; the authors do not bear any clinical responsibility.
- The DCRC at UNSW Sydney does not accept any liability for any injury, loss or damage incurred by use of or reliance on the information.
- The information in these documents is not intended as a substitute for professional medical advice, diagnosis or treatment. If this information raises questions or concerns regarding care providers' personal health they should always seek the advice of a qualified health professional.

# 1 - Overview

## Acknowledgements

### Acknowledgement of Country

We acknowledge the Traditional Custodians of this land. We pay respect to Aboriginal and Torres Strait Islander Elders both past and present, and extend that respect to other Aboriginal and Torres Strait Islander peoples and their culture. We acknowledge the diversity of bodies, genders, identities, sexualities and relationships included in the traditions and culture of Aboriginal and Torres Strait Islander peoples.

### Acknowledgement of LGBTI Elders

We pay respect to elders and allies in the lesbian, gay, bisexual, transgender and intersex communities. We recognise the limitations of the 'LGBTI' acronym and extend our acknowledgement to include those who are part of the wider diversity of bodies, genders, sexualities, relationships and identities. We acknowledge all those whose efforts in the past have helped to make today's conversations and learnings possible.

We thank The Hon. Michael Kirby AC CMG, former Justice of the High Court of Australia for his support and endorsement of this project.

### Funding

This project was funded by a grant from the DCRC Knowledge Translation Program. Additional benefactors including the Sydney Rams Tenpin Bowling Club, Alan Welch, the Cronulla Gay Group and the Pollys Club are gratefully acknowledged.

### Consultation and review

Consultation for this resource was undertaken with consumers, Government

representatives, LGBTI peak bodies, researchers, experts and those experienced in providing services to LGBTI people with dementia. An advisory group was established to provide expert guidance throughout the project:

- Ely Brammesan, Health State Network, Australian Government Department of Health
- Melanie Dicks, LGBTI Working Group, Uniting
- Samantha Edmonds, Silver Rainbow Ageing and Aged Care projects, National LGBTI Health Alliance
- Sally Lambourne, Policy, Research and Consultancy Dementia Australia NSW
- Jen Lindon Dementia Policy Section, Ageing and Sector Support Branch, Australian Government Department of Health
- Charles Lo, Bupa Aged Care, Ashbury
- Kimberly Olsen, (previously) Training and Engagement ACON
- Laurel Walter, (previously) The Gender Centre Over 55 Support
- Fiona White, University of NSW
- Peter Wojtowicz, Health State Network, Australian Government Department of Health

Additional consultation was undertaken with the following organisations, carers and experts:

- Tekwabi Giz advisory body to the National LGBTI Health Alliance, comprising Aboriginal and Torres Strait Islander Brotherboy, Sistergirl and LGBTIQ communities
- Catherine Barrett, Celebrate Ageing

# 1 - Overview

- Elizabeth Beattie, DCRC QUT
- Tony Briffa, Intersex Human Rights Australia
- Pauline Crameri, Val's Café, Australian Research Centre in Sex, Health and Society, La Trobe University
- Kathi, Bisexual Alliance Victoria
- Jenna Macnab, Diversity Services Department of Justice and Attorney General
- Pearlie McNeill, partner and carer to Meg
- Carmelle Peisah, Capacity Australia
- Meredith Butler, Carers Australia Victoria Education Services (LGBTIQ)
- Marjon Robken, partner and carer to Suzanne
- David Ross-Smith, partner and carer to David
- Yvonne Santalucia, Multicultural Aged Officer, South Western Sydney Local Health District
- Alan Welch, former Adult Literacy and Numeracy teacher TAFE NSW
- Outcomes from a comprehensive review of the academic and grey literature were also included.
- Although publications in the area of LGBTI-inclusive practice are increasing, this is an emerging area of academic literature and research. Where possible peer-reviewed publications have been sourced however grey literature such as reports and other resources which typically do not undergo peer review has also been cited. While this literature can appropriately describe issues and situations relevant to older LGBTI peoples the information may not be generalisable to all those included in this group.

- Approval to undertake this project was obtained from UNSW Sydney (University of NSW), Human Research Ethics Advisory Biomedical Panel (HC16573).

## References

1. Burns K, Jayasinha R, Tsang R, Brodaty H. Behaviour Management: A Guide to Good Practice, Managing Behavioural and Psychological Symptoms of Dementia Sydney: DCRC, University of NSW; 2012.
2. Markwell H. Loaded meanings: the narrative of behaviour. Australian Journal of Dementia Care. 2016;5(3):12-6.
3. Westwood S. Dementia, women and sexuality: How the intersection of ageing, gender and sexuality magnify dementia concerns among lesbian and bisexual women. Dementia. 2016;15(6):1494-514.
4. McGovern J. The forgotten: dementia and the aging LGBT community. Journal of gerontological social work. 2014;57(8):845-57.
5. 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). file:///D:/Users/z3239233/Downloads/sub09\_GRAI.pdf Perth Australia, GRAI 2013.
6. National LGBTI Health Alliance. Letter to Senate Standing Committee on Community Affairs 2013.
7. Crameri P, Barrett C, Latham JR, Whyte C. It is more than sex and clothes: Culturally safe services for older lesbian, gay, bisexual, transgender and intersex people. Australasian Journal on Ageing. 2015;34:21-5.
8. National LGBTI Health Alliance. Championing Inclusion: A Guide to creating LGBTI inclusive organisations. Sydney: National LGBTI Health Alliance; 2014.
9. Intersex Human Rights Australia. Making your service intersex-friendly In: ACON IHRAa, editor. Sydney, Australia 2014.
10. Barrett C, Stephens K. Beyond: 'we treat everyone the same'. A report on the 2010 – 2011 program: How2 create a gay, lesbian, bisexual, transgender and intersex inclusive service. Melbourne Australia: Gay and Lesbian Health Victoria; 2012.
11. Barrett C, Crameri P, Lamourne 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.

# 1 - Overview

## Contents

### Fact sheet 1: Overview

- Key Learning Objectives
- Disclaimer
- Acknowledgements

### Fact sheet 2a: Introduction

- Key LGBTI terminology and definitions
- Older LGBTI peoples - important statistics

### Fact sheet 2b: Human and legal rights rights of LGBTI peoples with dementia

### Fact sheet 3: Managing changed behaviours or behavioural and psychological symptoms of dementia (BPSD)

### Fact sheet 4: The influence of personal history and lived experience

- Invisibility of older LGBTI peoples
- The influence of historical discrimination, exclusion and trauma
- Resilience
- Disclosure and identity in dementia

### Fact sheet 5: Additional considerations for bisexual people

### Fact sheet 6: Additional considerations for transgender people

### Fact sheet 7: Additional considerations for intersex people

### Fact sheet 8a: Additional considerations for Aboriginal and Torres Strait Islander peoples who identify as LGBTI, Brotherboy or Sistergirl

### Fact sheet 8b: Additional considerations for LGBTI peoples from culturally and linguistically diverse (CALD) backgrounds

### Fact sheet 8c: Additional considerations for LGBTI peoples living in regional and remote areas

### Fact sheet 8d: Additional considerations for LGBTI peoples with young onset dementia (YOD)

### Fact sheet 9: The mental and physical health of a person with dementia who is L, G, B, T or I

- People living with human immunodeficiency virus (HIV)

### Fact sheet 10: The impact of the care environment

- Service providers and staff

### Fact sheet 11: The importance of care relationships

- Family of origin and family of choice
- LGBTI carers' experiences

### Fact sheet 12: Additional considerations for communicating with LGBTI peoples with dementia

- Language and terminology
- Communicating with transgender people
- Communicating with intersex people

### Fact sheet 13: Supporting an inclusive approach to service provision and BPSD management

- Service providers and their staff
- Peak bodies
- Challenges and enablers to implementing LGBTI-inclusive care practices
- Everyday strategies to assist in the management of BPSD

### Glossary