# LGBTI and Dementia

Understanding changes in behaviour Published by HammondCare 2022 Sydney, Australia hammond.com.au publishing@hammond.com.au ISBN: 978-0-6486790-4-2 © HammondCare

Except as permitted under the Australian Copyright Act 1968, no part of this book may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise without prior permission of the copyright owner and the publisher of the book.

Imagery content is being used for illustrative purposes only, and in some cases a person depicted in the content is a model. Design: Fuller Studio.



A catalogue record for this book is available from the National Library of Australia.

**Important:** Dementia care knowledge and research is continually changing and as new understanding develops, so too does the support provided for people with dementia. All care has been taken by the authors and publishers, as far as possible at time of publication, to ensure information is accurate and up-to-date. You can contribute to future editions of this book by going to dementia.com.au

The information in this book is not intended to be used to diagnose, treat, cure or prevent any disease, nor should it be used for therapeutic purposes or as a substitute for your own health professional's advice. The authors do not accept liability for any injury, loss or damage incurred by use of or reliance on the information contained in this book.

Dementia Support Australia is committed to providing excellence in dementia care. Older and younger people living with dementia deserve services that are designed and delivered based on evidence and practice knowledge of what works. This is achieved through individually tailored support and interventions, working in partnership with people living with dementia and their carers.

This booklet has been developed for aged care staff who are caring for lesbian, gay, bisexual, transgender and intersex (LGBTI) people. It aims to provide an understanding of some of the issues LGBTI people may have faced at different times in their lives and how this may impact on changes in behaviour if the person develops dementia.

Terminology used in this resource may not be familiar to everyone, therefore a glossary of terms has been added to the back of this booklet.

# Contents

Foreword	2
Introduction	4
I. LGBTI history in Australia	6
2. Aged Care Quality Standards	10
3. Dementia	12
HIV-associated dementia	13
4. Changes in behaviour	14
Trauma and stress	15
Getting to know the person	16
Language	18
Cultural considerations	19
First Nations peoples	20
Environment and engagement	20
Relationships, intimacy and sexu	Jality <b>21</b>
The need for intimacy and conte	act <b>22</b>
Mental and physical health	24
Providing inclusive personal car	e <b>26</b>

Useful services	28
Useful resources	31
Glossary of terms	33
References	36



## Foreword

LGBTIQ+ Health Australia (LHA) is delighted to be part of this co-designed resource which brings together the collective expertise of Dementia Support Australia (DSA) and LHA, to provide an evidence based and traumainformed approach to deliver support for LGBTI people living with dementia.

This useful resource draws on case studies to illustrate how an individualised approach to care can support a person living with dementia to have the best quality of life and engagement within a residential care setting.

People experience dementia in their own individual way and being lesbian, gay, bisexual, trans and gender diverse and/or a person with innate variations of sex characteristics can bring additional and unique challenges. Living with dementia as an LGBTI person can be especially isolating for many reasons. This may include estrangement from family because of who they are or separation from their communities and chosen family when moving into residential care. For many intersex people they may suffer lifelong physical and emotional effects from medical interventions, and related shame and secrecy. Aged care services that lack LGBTI inclusive practices can further increase this isolation and negatively impact on the wellbeing of older LGBTI people.

At LHA we see how LGBTI older people currently accessing aged care services have experienced profound discrimination, harassment and violence in their lives as they have lived through an era of criminalisation and lack of recognition of LGBTI rights and how these experiences, particularly trauma and medical violence, can impact a person's behaviour if they develop dementia.

With improved knowledge of the lived experiences of LGBTI older people, aged care workers can better understand the behaviour of those living with dementia. This holds the key to providing culturally safe services including welcoming environments, inclusive practices and individualised care plans. The Aged Care Quality Standards and Aged Care Diversity Framework referred to in this resource highlight the importance and requirement to embed diversity in the design, delivery and at the core of aged care.

I trust this resource will help care staff support and care for LGBTI residents living with dementia. Thanks to the DSA team for their collaboration during the development process drawing on the lived experience of our members to create a respectful and informative resource.

#### **Nicky Bath**

CEO

LGBTIQ+ Health Australia



# Introduction

LGBTI communities are a diverse group of people with a variety of backgrounds, experiences and needs. There are LGBTI people with a strong connection with LGBTI communities while others may not feel they belong to this group or feel uncomfortable being included in the abbreviation 'LGBTI'. While it is good to be aware of the shared issues or experiences of LGBTI people, it is also important to acknowledge their diverse individual life stories.

Many older LGBT people have lived through a time when expressing their sexuality or gender identity could lead to stigmatisation, discrimination. persecution. imprisonment and tensions or separation from family. Some LGBT people live in fear of having family or community members discovering their gender identity or sexual orientation and as a result being rejected and isolated. Due to this, many older LGBT people have learned to hide their sexuality, gender identity and relationships from others including health care providers. Growing up in a time where society expected people to get married and have children, older LGBT people may have been or remain in heterosexual relationships. Some older LGBT people may have only expressed their sexualities and identities much later in life and some not at all.

For people born with an intersex variation, their experience is often different from LGBT people. There has been a history of coercive and involuntary medical interventions to normalise their sex characteristics. This included surgical interventions occurring in infancy or childhood. The purpose of many of the interventions was to 'normalise' their bodies rather than treating a medical concern. For many people who have an intersex variation. these unnecessary surgeries have caused ongoing physical and psychological harm. Historically, intersex people and the parents of intersex children did not get full access or accurate information about diagnostic facts and medical interventions. Not providing this information was thought to help people conform to conventional sex and gender norms. These practices are no longer considered appropriate.<sup>1</sup>

More recently, changes to legislation and policy have increased awareness and supported a greater sense of community acceptance; however, many LGBTI people still experience discrimination and rejection. This discrimination extends into government services such as accessing health care and aged care. For older people who do access services, they may not tell anyone that they are LGBTI, and try to hide their sexual orientation, gender identity or bodily differences due to ongoing fear of discrimination and violence.

While it is good to be aware of the shared issues or experiences of LGBTI people, it's also important to acknowledge their diverse individual life stories.

# LGBTI history in Australia









#### History timeline

It's important to understand the historical context likely to be familiar to older LGBTI people as well as the possible impacts of this history on the individual in the current context. The timeline below provides an overview of the key events in the last 80 years that have shaped the experiences of older LGBTI people in Australia.

## 1940s

People who are same sex attracted were considered mentally ill and often subjected to cruel treatments in psychiatric facilities, including castrations, torture drugs, shock therapy and lobotomies. Aversion therapies in the form of electric shocks took place until the mid-1980s.

## 1973 1976/77

The term 'homosexuality' is removed from the American classification of mental disorders (DSM).

More than 100 men were arrested in Victoria for homosexuality in a law enforcement campaign. Police posed as homosexuals to entrap gay men.

## 1978 1980s

The first Mardi Gras event was held in Sydney, ending with 53 arrests and brutal police bashings.

Start of the HIV/AIDS epidemic in which gay men were disproportionally impacted. Increased community fear and anxiety exacerbated existing discrimination and persecution. Hate crimes also occurred, which the NSW Police Force didn't properly investigate.

1982	NSW was the first state to pass anti-discrimination laws against gay people. However, for another two years male acts of homosexuality were still illegal. The federal government was the last jurisdiction in Australia to introduce LGBTI anti- discrimination protections three decades later in 2013.
1990	The World Health Organization declassified homosexuality as a mental disorder from its classification (ICD).
1997	Tasmania was the last state in Australia to decriminalise homosexuality, 22 years after the first state, South Australia.
1999	Start of an annual Bi Visibility Day to highlight biphobia and to help people find the bisexual community.
2009	Same-sex couples have their de facto relationships legally recognised and are now entitled to the same benefits as opposite-sex couples.
2013	The Australian Senate reports on an inquiry into involuntary or coerced sterilisation, including for intersex people. This world-first parliamentary inquiry on intersex health and rights included 15 recommendations. None of the recommendations have been implemented.

## 2013

The Australian Government introduces guidelines on the recognition of sex and gender. People are now able to choose to identify as a gender other than the sex they were assigned at birth or may identify as not exclusively male or female. Gender can be changed in official records.

## 2017

Same-sex marriage is legalised Australia-wide after 22 unsuccessful attempts in the Federal Parliament since 2004. Although this was seen as a positive step for LGBTI rights, research has since shown this was a traumatising time for many LGBTI communities because of negative media messages and hatred.

## 2019

Being transgender is no longer classified as a mental health disorder by the World Health Organization.

## 2020

South Australia was the last state in Australia to scrap the so-called 'gay panic defence'. This was an argument used in court to downgrade murder charges to manslaughter by claiming that the defendant was provoked into violence by a sexual advance from the victim.

## 2021

The Australian Human Rights Commission releases a report recommending significant reform to protect the human rights of people born with variations in sex characteristics, particularly around decision-making on medical interventions.

# Aged Care Quality Standards

For LGBTI people, considering or accessing aged care and aged care services can be stressful. The Aged Care Quality Standards provide a framework that ensures that every person in Australia has the right to access quality, inclusive and culturally safe aged care services that meet their individual needs and respect their background and life experiences. These rights are described in the Aged Care Quality Standards and more specifically Standard 1.<sup>2</sup>

#### Australian Aged Care organisations will have to demonstrate the following:

- a) Each consumer is treated with dignity and respect, with their identity, culture and diversity valued.
- b) Care and services are culturally safe.
- c) Each consumer is supported to exercise choice and independence, including to:
  - make decisions about their own care and the way care and services are delivered; and
  - ii. make decisions about when family, friends, carers or others should be involved in their care; and
  - iii. communicate their decisions; and
  - iv. make connections with others and maintain relationships of choice, including intimate relationships.

- d) Each consumer is supported to take risks to enable them to live the best life they can.
- e) Information provided to each consumer is current, accurate and timely, and communicated in a way that is clear, easy to understand and enables them to exercise choice.
- f) Each consumer's privacy is respected, and personal information kept confidential.

These standards form the foundation of the expected level of care for how LGBTI people should be treated in aged care along with the Aged Care Diversity Framework action plans (see Useful resources).

# **3.** Dementia

Due to past life experiences, accepting and entering aged care may be more difficult for older LGBTI people living with dementia than for people who are not LGBTI because of fear of discrimination and mistreatment by healthcare providers and/or others living in residential aged care. Because of this, LGB people who have previously been open about their sexuality may choose to hide their sexual orientation and expression while living in residential aged care. For intersex people, there is often forced disclosure of their intersex status due to a physical difference, extensive scarring or having unique personal care needs. Transgender people may not have a choice but to reveal their gender identity because of physical appearance or their need for specific medication.

Changes experienced due to dementia can be an extra complicating factor. The person may be unable to express their needs and wishes and therefore may not receive the individualised care that affirms them as an LGBTI person. It is therefore important that LGBTI people living with dementia are adequately supported around their sexuality, gender and bodily diversity with respect and dignity.

## HIV-associated dementia

Many diseases can cause dementia, including HIV. HIV is a disease which targets a person's immune system and can weaken a person's defence against many infections. The group most affected by HIV in Australia is men who have sex with men.<sup>3</sup> HIV-associated dementia is becoming less common in Australia, however other forms of HIV-associated neurocognitive disorders (HAND) are increasingly identified in older people living with HIV.<sup>4</sup> HAND consists of three subtypes: asymptomatic neurocognitive impairment, mild neurocognitive disorder and HIVassociated dementia.<sup>5</sup>

There are several options for treating HIV-associated dementia, with early diagnosis and ongoing HIV treatment being important.

# Changes in behaviour

Many people with dementia experience changes in behaviour. This may be expressed in different ways including anxiety, restlessness, physical aggression, apathy, and withdrawal. Although changes in behaviour may be related to the progression of dementia, many are a consequence of or impacted by other internal and external factors. In this section, we will discuss potential causes of changes in behaviour and considerations specific to LGBTI older people.

## **Trauma and stress**

LGBTI people may experience or have experienced discrimination, loss and fear during their lives because of their sexuality, gender identity or variations in sex characteristics. This may have resulted in trauma, anxiety and stress. Reliving past traumatic experiences may be expressed through changes in behaviour for a person living with dementia. For older people in general, moving into aged care may lead to feelings of loneliness, loss of autonomy and increased dependence on others. LGBTI people may experience further stress linked to distrust of health services, medical trauma, potential discrimination from staff and other residents, suppressing needs, lack of recognition of life partners, having bodily differences and few opportunities to meet other LGBTI people.

Capturing a person's social history helps to understand the

person, their needs, and reasons for changes in behaviour. Be mindful that this process may be stressful for the person and can induce anxiety. Creating a safe environment is essential for people to feel comfortable sharing about themselves as well as communicating their needs and for some that will be LGBTI-inclusive. For example, consider if your service visibly acknowledges the diversity of people (e.g. brochures, posters, celebrations of LGBTI visibility days and events) and if the forms people need to complete as part of their care (e.g. intake forms, assessment) are inclusive (see Useful resources). Reaardless of how LGBTI-inclusive your service is, some people will choose not to tell you they are LGBTI and this needs to be respected.

Refer to the DSA 'Understanding the impact of trauma and stress for LGBTI people with dementia' helpsheet to read more about the impact that past trauma and stress may have on the behaviours of LGBTI people living with dementia.

Visit: dementia.com.au/ resources/library

### Getting to know the person

Staff had noticed Claire was becoming more withdrawn, not wanting to participate in any of her regular activities and preferring to stay in her room. The care team were also concerned about her increasing anxiety when staff provided personal care. She was becoming more resistive, often pushing staff away or even crying and appearing highly distressed at times.

So that staff could understand how to best support Claire at this time, they spoke with both her and a trusted friend about her life story. Staff learned that Claire was assigned male at birth and being the eldest child in the family was often asked to look after her younger siblings. As an adult Claire married and had two children. In her early fifties, she underwent gender affirmation surgery. Claire's siblings and children did not understand her transition and as a result distanced themselves from her.

Claire has long believed that affirming her gender cost her both her family and her role as a parent; she no longer felt useful and became a very private person, often finding it hard to trust others and form relationships. It was felt that these events were contributing to a lack of trust, social isolation, and anxiety, which Claire was unable to communicate due to her dementia.

With a better understanding of Claire, staff worked to develop a relationship to make her feel safe and earn her trust. While spending time with Claire, they would talk about topics they knew she was interested in and that were not care related such as music and hobbies. They also gave compliments on Claire's appearance and praise when appropriate. To reduce isolation and loneliness, staff encouraged Claire to listen to her favourite music outside of her room and introduced her to a small group of residents who had similar interests.

An external organisation was also brought in to provide education to care staff about the needs of transgender people.

## Language

Language used by LGBTI people to refer to themselves and language used by the general public to describe LGBTI people have changed over time and can be different between generations and cultures. There are also individual differences in how people talk about themselves. For example, 'gay' is a word previously associated with men but may also be used by a lesbian woman to refer to herself. A woman who was assigned male at birth may refer to herself as a trans woman or just a woman. Some intersex people identify as LGBT, but many of them do not and identify as heterosexual and/or cis-gendered. LGBTI people may use one term or a range of terms and may also prefer not to use terms at all (see Glossary).

It's important to be aware of how people talk about themselves and to ask how they prefer to be referred to. Using the correct terms and pronouns is affirming and avoids bringing back unpleasant memories or creating uncomfortable situations. Terms It's important to be aware of how people talk about themselves and to ask how they prefer to be referred to.

may not be the same in every situation and may depend on whether the person is in a private or public setting.

Think about the language used in everyday conversation and make sure it's inclusive and respectful. For instance, talk about a partner instead of a wife/husband, about important people in someone's life instead of family.

# Cultural considerations

LGBTI people from culturally and linguistically diverse (CALD) backgrounds often have a different experience with their intersex variation, gender identity or sexual orientation than people who are not from CALD backgrounds. They can experience added trauma or stress due to discrimination from both racism and in relation to their sexuality, gender identity or intersex variation. Some LGBTI people may have come from countries where being openly LGBTI may result in legal implications such as imprisonment or even the death penalty.6

Certain cultures or faiths can contribute to a person suppressing their sexual identity or feelings due to shame. They may take significant steps and compromises to conform to their family or community expectations. Some people may never have been able to express themselves or connect with others who are LGBTI especially if they have limited English language skills, are newer migrants or never had access to resources in their first language. Discrimination against LGBTI people from diverse cultural backgrounds or faiths might come from outside as well as within the LGBTI community. This experience may change when a person enters a faith-based environment, such as a nursing home.<sup>7</sup> They may experience less racism within an environment that has many members of their community, but may then experience discrimination based on their sexuality, gender or bodily diversity.

All these different life experiences may present itself as changes in behaviour while living with When capturing dementia. someone's life history, consider if their cultural background has impacted how the person feels about being LGBTI and if this is a cause for additional stress or trauma. There are different peer support groups and services available for CALD LGBTI people (see Useful services). Also, talk to the person, their family or 'chosen family' about what is culturally important for them and to best express themselves.

## **First Nations peoples**

There is limited information available about the experiences of LGBTI First Nations peoples in Australia either before or after colonisation.<sup>8</sup> Many older First Nations peoples have experienced significant trauma due to separation from their families, their culture, their land and access to spiritual practice. Older LGBTI First Nations peoples may also deal with other complex challenges including the experience of racism from outside their community and experiencing homophobia, biphobia, interphobia and transphobia from within their community. However, many First Nations peoples' family, community and spiritual connections are very supportive of their wellbeing.

Other identities to be aware of are First Nations transgender peoples who may be referred to as Sistergirls (women or female spirits who were assigned male at birth) and Brotherboys (men or male spirits who were assigned female at birth). Brotherboys and Sistergirls are unique to Australia's First Nations peoples. However, not



all First Nations peoples who are transgender and gender diverse will identify as Sistergirls and Brotherboys.

# Environment and engagement

When people move into a care home it's important to make sure they feel comfortable in their new environment. For some people this might include displaying photos of life partners in their room or a rainbow flag which may demonstrate it's a safe place for them. Choosing a care home that supports, acknowledges and respects diversity, and allows people to express themselves is important.

Loneliness can increase after moving into a care home. Engage the person in activities they like and are familiar with. Avoid making assumptions about what the person likes or dislikes, based on their sexual orientation or gender identity. For example, if a person is gay, do not assume they wouldn't want to watch football on TV with other residents. There are LGBTI organisations that provide older LGBTI people with visitors to reduce social isolation or loneliness (see Useful services).

## Relationships, intimacy and sexuality

Recognition of and respect for the diversity of intimate relationships and family of choice is essential to meet the needs of LGBTI people living with dementia. While a person's biological family may not have been involved in parts of their relative's lives because of conflict, they may want to be involved in the decision-making process about their care. This may be a source of stress for the person living with dementia and their partner or family member of choice. Be mindful of the LGBTI person's wishes in this space and respect them.

Even in environments that recognise and affirm everyone's sexual expression and gender identity, LGBTI people living in aged care and their partners may encounter significant barriers in expressing themselves fully. They may not feel comfortable disclosing their relationship in this new situation or have never expressed their relationship in public and may introduce their partner as 'a good friend'.

Every person (with or without an intimate partner) may have the need for regular touch and intimacy and may have sexual needs. Not having these needs fulfilled may result in changes in behaviour.

Read more about relationships, intimacy and sexuality, and the impact it may have on the behaviour of LGBTI people living with dementia in the DSA 'Supporting sexuality and intimacy for LGBTI people living with dementia' helpsheet.

Visit: dementia.com.au/ resources/library



FOR

#### Since moving into a care home, Grant, a 72-year-old gay man, had started to use graphic and explicit sexual language with other residents. At times Grant asked other men to remove their clothes and has been seen approaching them in their room.

The care home contacted Dementia Support Australia (DSA). The Dementia Consultant who visited Grant observed that he was very emotional and tearful, often crying spontaneously. Grant told the consultant he had 'nothing to live for' and 'would kill himself if he could'.

Grant has a history of depression and staff commented that he is usually quite teary before he approaches other residents. The Dementia Consultant spoke with Grant's two cousins who grew up with him. They reported that Grant would be 'horrified' if he knew what he was saying; he had never used language like that before. They also shared that although Grant never married, he had been with his partner for 25 years before he died from AIDS.

The Dementia Consultant advised care staff that although Grant's needs appear sexual, he may also just be seeking intimacy and connection. This could mean spending time with another resident he feels comfortable with, particularly after he has been upset. The Dementia Consultant also learnt that Grant and his partner were '78ers' who protested at the first Mardi Gras in 1978 and experienced police violence and brutality. They were also heavily involved in HIV/AIDS activism in the 1980s. A link to the local LGBTI community was recommended to engage a volunteer who could be matched with Grant and visit the care home to socialise and share stories about the gay rights movement. Staff found out that Grant loved gardening and bought gardening equipment as well as books with colourful photos and seasonal information. Increasing privacy was recognised as an issue, so signs were placed on the door to indicate if he was in the room.

These strategies helped Grant to engage with more activities and he became close friends with another resident. As Grant's mood improved, his explicit language ceased completely.

# Mental and physical health

Older LGBTI people may experience different health outcomes compared to people who are not LGBTI. Pressure to conform to gender norms, the desire to fit in and rejection by family may negatively impact on a person's mental health. Evidence shows that people who are LGBTI have higher rates of depression and anxiety than people who are not LGBTI.<sup>9</sup>

There may also be an effect on physical health; for example, physical check-ups may have been avoided due to distrust and fear of accessing health services. Underlying health conditions add additional complexity to the care and support of a person living with dementia. People with an intersex variation and transgender people may use hormone therapies. For many intersex people this is vital for them to maintain optimal health. For transgender people this

affirms their gender and supports emotional and psychological wellbeing. It's important to be aware of this when someone moves into residential aged care as suddenly ceasing hormone treatment use can result in (an increase in) depression. Medical checks such as breast checks and cervical screening for trans men and prostate checks for trans women are part of ongoing health monitoring and are important to undertake to rule out any unexpected health issues. These checks need to be undertaken with sensitivity as transgender people may not like to acknowledge physical body parts that don't align with their identity. Transgender people may also refer to their body parts by different names, so it's important to communicate appropriately around their bodies to ensure that they feel safe disclosing any changes that may occur in these areas without fear of judgement.

A person's intersex variations may be identified in the earlier stages of life - before or at birth - and may only become evident during puberty or when someone is trying to become pregnant. Because their bodies are perceived as being different, people who are intersex can experience social stigma and many people have had medical procedures to 'fix' their bodies to fit medical norms of being male or female. This can have an impact on mental health and physical health. Early and unnecessary interventions can have consequences such as shame. loss of sexual function and sensation. loss of choice and many people live with ongoing trauma.<sup>10</sup> These feelings might be relived in all stages of life and intensified while living with dementia, expressed through changes in behaviour such as withdrawal. distrust of health services and anger.

Feelings might be relived in all stages of life and intensified while living with dementia, expressed through changes in behaviour such as withdrawal, distrust of health services and anger. Providing inclusive personal care Tom is a 70-year-old man, who has lived in an independent living unit for 10 years. Before his diagnosis of dementia, Tom had been accessing support with cooking, shopping and cleaning around his home. However, due to the progression of his dementia, he has recently received support with showering and being taken to medical appointments. Staff noticed that Tom had stopped showering and was also refusing services, even for supports he received in the past. Tom would become very agitated and upset if anyone brought up his resistance to receiving services. Overall, Tom was becoming more withdrawn from his friends within the community and was also refusing to attend medical appointments.

Staff made a referral to Dementia Services Australia (DSA). Tom told the Dementia Consultant that he had a support worker come over to help him with showering and it had made him feel uncomfortable. Tom said that he has androgen insensitivity syndrome (AIS), which has caused some physical bodily difference. Tom mentioned that he did not tell people about it and the only people who knew before this were his GP and endocrinologist. Tom advised that the first time a support worker helped him into the shower, they made some comments about his body, especially his abdominal scars and genitals. He said that it was not the first time someone had commented on his body in a negative way, and he had many people in his past harass him for his difference.

With permission from Tom, the Dementia Consultant contacted Tom's provider and spoke with his care coordinator. A complaint was lodged with the provider and a new plan was put in place. Tom was able to meet the two new support workers, who spent some social time with Tom and built trust before providing personal care. The support also limited the amount of physical exposure Tom had to undergo during personal care activities. These strategies supported Tom to feel more comfortable, supported and confident. He has once again started to engage with friends in the community and now looks forward to having his support workers visit.

# **Useful services**

## **LGBTI Health**

#### LGBTIQ+ Health Australia

LGBTIQ+ Health Australia is the national peak health organisation in Australia for organisations and individuals that provide healthrelated programs, services and research focused on lesbian, gay, bisexual, trans/transgender, intersex, queer and other sexuality, gender and bodily diverse (LGBTIQ+) people and communities.

The LGBTIQ+ Health Australia website has a list of services and supports for LGBTI older people and people providing care. This includes social support programs that provide LGBTI older people with visitors to reduce social isolation or loneliness, mentoring and support programs, advocacy and support for people living with HIV.

#### Visit: lgbtiqhealth.org.au/ services\_and\_supports

Aged care workers can access (educational) resources from the Silver Rainbow and Community Resources Page.

Visit Silver Rainbow: lgbtiqhealth. org.au/silver\_rainbow

#### Visit Community Resources:

lgbtiqhealth.org.au/ communityresources

# LGBTI First Nations services

### **Black Rainbow**

Black Rainbow is a national advocacy platform and touchpoint for Aboriginal and Torres Strait Islander LGBQTI peoples. They support Aboriginal and Torres Strait Islander LGBQTI people through a variety of community projects and initiatives including training.

#### Visit: blackrainbow.org.au

### BlaQ

BlaQ is an Aboriginal Corporation that was established to strengthen visibility and advocacy for Aboriginal and Torres Strait Islander LGBTQ+ community. BlaQ aims to foster pathways that provide informed and authentic representation that positively impacts the social and emotional wellbeing of Aboriginal and Torres Strait Islander LGBTI peoples.

Visit: blaq.org.au

# LGBTI multicultural services

#### **Rainbow Cultures**

Rainbow Cultures is an online directory of groups and services for culturally and linguistically diverse (CALD) LGBTI communities in NSW and more broadly Australia. It includes multicultural and multilingual LGBTI organisations, groups and services that cater to or are welcoming of LGBTI people from CALD communities.

Visit: rainbowcultures.org.au

## **Intersex Australia**

Intersex Human Rights Australia is a national charity by and for people with innate variations of sex characteristics. They promote human rights, health and bodily autonomy. Their goals are to help create a society where intersex people are not stigmatised, and where their rights are recognised. Delivering training, studies and peer and family support.

#### Visit: ihra.org.au

## **LGBTI training**

#### **Silver Rainbow**

The Silver Rainbow 'LGBTI Aged Care Awareness Training Project' is specifically designed to provide information about older LGBTI people. It's managed by LGBTIQ+ Health Australia and is delivered collaboratively with project partners across every state and territory in Australia.

Visit: lgbtiqhealth.org.au/silverrainbow-training

#### **Yellow Tick Training**

The Yellow Tick is a communityled initiative that assists groups to develop intersex inclusive and affirmative practices for programs, clients and staff. They provide a policy and program review service alongside training and intersex specific resources.

Visit: darlington.org.au/yellowtick

#### Transgender and Gender Diverse

Services providing training and support:

A Gender Agenda: genderrights.org.au

Trans Hub: transhub.org.au Transgender Victoria: tgv.org.au The Gender Centre (NSW):

gendercentre.org.au

## Dementia

#### **Dementia Support Australia**

Dementia Support Australia (DSA) provides advice and support for carers of people with dementia experiencing changes in behaviours. The role of DSA is to improve the quality of life for people living with dementia and their carers. DSA does this by working in partnership with the person living with dementia and their care network to understand the causes or triggers that led to changes in behaviour. DSA offers support 24 hours a day, 365 days a year throughout Australia. Our partnership with LGBTIQ+ Health Australia enables DSA to access LGBTI specific strategies and approaches.

**Contact details:** Phone 1800 699 799 or visit dementia.com.au

#### Dementia Australia

Dementia Australia provides information and education on dementia and runs programs and services such as counselling and support groups. They can also help you to find the right support in your area.

#### **Contact details:**

Phone 1800 100 500 or visit dementia.org.au

#### **Dementia Training Australia**

Dementia Training Australia is a consortium funded by the Australian Government to provide nationwide education and training on the care of people living with dementia.

Contact details: dta.com.au

## **Useful resources**

 Australian Bureau of Statistics. Standard for sex, gender, variations of sex characteristics and sexual orientation variables. January 14, 2021.

https://www.abs.gov.au/ statistics/standards/standardsex-gender-variations-sexcharacteristics-and-sexualorientation-variables

 Barrett C, Crameri P, Lambourne S, Latham J. We Are Still Gay
An Evidence-Based Guide to Inclusive Services for LGBT People Living with Dementia. Australian Research Centre in Sex, Health and Society; 2015.

https://www.dementia.org.au/ sites/default/files/NATIONAL/ documents/Dementia-Narrative-Resource.pdf  Department of Health. Actions to Support Older LGBTI People: A Guide for Aged Care Providers. Department of Health; 2019.

https://www.health.gov.au/ resources/publications/ actions-to-support-lgbtielders-a-guide-for-aged-careproviders

Department of Health. Actions to Support Older LGBTI People: A Guide for Consumers. Department of Health; 2019.

https://www.health.gov.au/ resources/publications/ actions-to-support-lgbtielders-a-guide-for-consumers

Hosking D, Hosking R, Orthia L, Ee N, Maccora J, McCallum J. Listening to LGBTI Seniors. National Seniors Australia, LGBTIQ+ Health Australia; 2021.

https://d3n8a8pro7vhmx. cloudfront.net/lgbtihealth/ pages/852/attachments/ original/1635824447/LGBT-report. pdf?1635824447  Latham J, Barrett C. We're people first: Trans Health and Ageing: An Evidence-Based Guide to Inclusive Services. Australian Research Centre in Sex, Health and Society; 2015.

https://www.latrobe.edu. au/\_\_data/assets/pdf\_ file/0004/814792/Trans-Ageing-And-Aged-Care-Project.pdf

 LGBTIQ+ Health Australia. LGBTIQ+ Health Australia fact sheet: ABS standard for sex, gender, variations of sex characteristics and sexual orientation. 2020.

https://d3n8a8pro7vhmx. cloudfront.net/lgbtihealth/ pages/710/attachments/ original/1610593682/ABS\_ Standards\_Factsheet\_-\_14\_ Jan\_2021.pdf?1610593682  Sage USA. Facts on LGBT aging. March 2021.

https://www.sageusa.org/wpcontent/uploads/2021/03/sagelgbt-aging-facts-final.pdf

 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):1494–1514.

## **Glossary of terms**

The glossary terms are based on 'Inclusive Practice'," 'Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables'<sup>12</sup> and 'LGBTIQA+ Communities Glossary of Common Terms'.<sup>13</sup>

**Bisexual** – A person who is primarily attracted emotionally/romantically and sexually to people regardless of their sex or gender.

**Cis-gender** – A term used to describe people whose gender corresponds to the sex they were assigned at birth.

Family of choice – People, or a group of people a person sees as significant in their life. It may include significant others, domestic partners, friends, and co-workers. Family of choice also may include none, all, or some members of family of origin. **Gay** – A man who is primarily attracted emotionally/romantically and sexually, to another man. The term is most commonly applied to men, although some women use this term as well.

**Gender** – Gender is a social and cultural concept. It is about social and cultural differences in identity, expression and experiences as a man, woman or non-binary person.

**Gender-diverse** – People whose understanding or performance of their gender does not conform to social expectations based on their sex assigned at birth.

**Gender identity** – A person's gender identity refers to an internal sense of oneself. It includes the feeling that oneself is masculine, feminine, neither, both or moving freely between or outside of the cultures gender binary.

Heterosexual – A woman who is sexually and/or romantically attracted to men or a man who is sexually and/or romantically attracted to women.

#### Homophobia / Biphobia / Transphobia / Interphobia –

Negative attitudes and feelings, including fear or hatred, towards LGBTI people often resulting in violence and discrimination.

Homosexual – A person who is sexually and/or romantically attracted to people of their own gender/sex.

**Intersex** – People whose physical characteristics are not typically female or male according to current medical norms. This may include variations in chromosomes, hormones, reproductive organs, genitals, and visible physical features.

**Lesbian** – A woman who is primarily attracted emotionally/romantically and sexually, to another woman.

**LGBTI** – An abbreviation that refers to a group of people with diverse sexual orientation, sex or gender identity including lesbian, gay, bisexual, transgender and intersex people. **Pronouns** – Words that take the place of a noun and are usually used to refer to people in gendered ways. Some gender-diverse or non-binary people may use nongendered pronouns instead. Typical pronouns are: She/her/hers He/him/his They/them/theirs.

**Queer** – A term used to describe a range of sexual orientations and gender identities. It should be noted that for older LGBTI people, this term is often associated with experiences of harassment, violence and trauma. Therefore, this term should generally not be used in the context of working with older people.

**Sex** – A person's sex is based upon their sex characteristics, such as their chromosomes, hormones and reproductive organs. While typically based upon the sex characteristics observed and recorded at birth or infancy, a person's sex can change over the course of their lifetime and may differ from their sex recorded at birth. **Sexual orientation** / **sexuality** – Emotional, romantic, sexual, or affection-related attraction towards others.

**Trans man** – A person who has transitioned from a woman to a man.

**Trans woman** – A person who has transitioned from a man to a woman.

**Transgender** (short: Trans) – An umbrella terms used to refer to people whose assigned sex at birth does not match their gender. A trans woman is a woman, a trans man is a man, and a trans nonbinary person is non-binary. The sex they were assigned at birth is irrelevant. **Transition** – The personal process(es) made by a trans or gender diverse person to live as their preferred gender. This may include a change of name (including legal documents), a chosen style of address and pronouns, changed appearance and surgical procedures or hormone therapy.

Variations in sex characteristics – Physical sex characteristics that do not conform to medical norms for female or male bodies.

# References

 Head to Health. Intersex people. Updated September 24, 2019. Accessed September 2021.

https://www.headtohealth. gov.au/supporting-yourself/ support-for/intersex

2. Australian Government Aged Care Quality and Safety Commission. Aged Care Quality Standards fact sheet. Updated July 23, 2021. Accessed December 2021.

https://www.agedcarequality. gov.au/resources/aged-carequality-standards-fact-sheet

3. The Australian Federation of AIDS organisations. HIV in Australia. Accessed September 2021.

#### https://www.afao.org.au/ about-hiv/hiv-in-australia/

4. The Australian Federation of AIDS organisations. Neurocognition and HIV. July 2013. Accessed December 2021.

#### https://www.afao.org.au/ article/neurocognition-andhiv/#n11

5. Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine. HIV-associated neurocognitive disorder. Accessed December 2021.

https://hivmanagement. ashm.org.au/hiv-associatedneurocognitive-disorder/

6. ILGA World. Sexual orientation laws in the world. Updated December 2019. Accessed September 2021.

https://ilga.org/sites/default/ files/ENG\_ILGA\_World\_map\_ sexual\_orientation\_laws\_ dec2019\_update.png

- 7. Pallotta-Chiarolli M, Sudarto B, Tang J. Navigating Intersectionality: Multicultural and Multifaith LGBTIQ+Victorians Talk about Discrimination and Affirmation. AGMC/MASC/DPC; 2021.
- Kerry SC. Sistergirls/Brotherboys: The Status of Indigenous Transgender Australians. International Journal of Transgenderism. 2014;15(3–4):173– 186

 9. LGBTIQ+ Health Australia. Snapshot of mental health and suicide prevention statistics for LGBTI people. Accessed September 2021.

#### https://www.lgbtiqhealth.org. au/statistics

10.Carpenter M. Bodily Integrity. Intersex Human Rights Australia. Updated March 24, 2021. Accessed September 2021.

#### https://ihra.org.au/bodilyintegrity/

 LGBTIQ+HealthAustralia.Inclusive practice – Understanding the differences: Lesbian, gay, bisexual, transgender and intersex people. Updated 2016. Accessed December 2021.

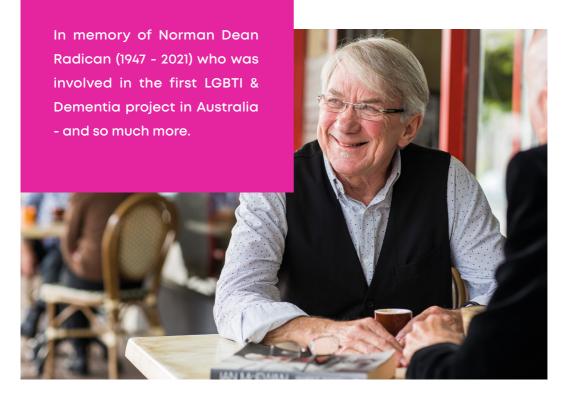
https://d3n8a8pro7vhmx. cloudfront.net/lgbtihealth/ pages/405/attachments/ original/1588024222/LGBTI\_ FactSheet\_Languages\_v2\_ WEB.pdf?1588024222 12. Australian Bureau of Statistics. Standard for sex, gender, variations of sex characteristics and sexual orientation variables. January 14, 2021.

https://www.abs.gov. au/statistics/standards/ standard-sex-gendervariations-sex-characteristicsand-sexual-orientationvariables/2020#introduction

13. Child Family Community Australia. LGBTIQA+ communities: glossary of common terms. Updated November 2019. Accessed December 2021.

https://aifs.gov.au/cfca/ publications/lgbtiqcommunities

## This booklet has been developed for aged care staff who are caring for lesbian, gay, bisexual, transgender and intersex (LGBTI) people. It aims to provide an understanding of some of the issues LGBTI people may have faced at different times in their lives and how this may impact on changes in behaviour if the person develops dementia.



This resource was developed in collaboration with LGBTIQ+ Health Australia.

Dementia Support Australia (DSA) is a free nationwide service led by HammondCare, funded by the Australian Government. Our role is to improve the quality of life for people living with dementia and their carers. We do this by getting to know the person with dementia to understand the causes of changes in behaviour and work together with carers, care workers and local networks to work out the best plan. We keep in contact with carers and care workers while they support the person with dementia to live well in their own environment.





Funded by the Australian Government A service led by HammondCare

DSA offers free support 24 hours a day, 365 days a year throughout Australia. Contact DSA or refer someone with dementia to our service through:

1800 699 799

dsa@dementia.co.au

dementia.com.au

Contact LGBTIQ+ Health Australia

$\bigcirc$	02 7209 6301
@	info@lgbtiqhealth.org.au
(www.)	lgbtiqhealth.org.au

