



# LGBTI and dementia

For people living with dementia who are Lesbian, Gay, Bisexual, Transgender or Intersex (LGBTI), their care partners, family and friends

## Acknowledgements

This guide was prepared by Dementia Australia for LGBTI people living with dementia, their families, friends and care partners.

This guide is based on discussions, consultations and input from LGBTI people. We would like to acknowledge everyone who contributed to the development of this resource.

Dementia Australia is committed to inclusive practice that values and respects diversity. The acronym LGBTI is used throughout this resource as its meaning is generally understood and familiar to readers. Dementia Australia acknowledges that the acronym LGBTI may not reflect the spectrum of potential diverse relationships, sexual orientations and sex or gender identities.



Disclaimer: This booklet is for information purposes. The tips and suggestions provided in this guide are general in nature and do not take into account your specific circumstances. We recommend that you seek professional advice in relation to any specific concerns or issues you may have. Dementia Australia and its employees are not liable for any error or omission in the information provided.

Funded by the Australian Government  
ISBN 978-1-921570-70-4

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# Foreword

## What is the aim of this resource?

This resource provides information to help people living with dementia who are LGBTI, their care partners, family and friends to remain as independent as possible, to be empowered to exercise choice and control and to be supported in an inclusive way.

Topics discussed in this resource include:

- Information about dementia
- Access to support and services
- Planning ahead
- Privacy, confidentiality and disclosure

## Why might people who are LGBTI find this resource useful?

People who are LGBTI share the same diversity and life experience as the broader community, however they may also have experienced social exclusion, isolation and discrimination. In some circumstances, they may continue to encounter similar issues as they seek support through the aged care or disability care system<sup>1</sup>.

The suggestions included in this resource are based on research conducted by Dementia Australia and feedback from people who are LGBTI.

<sup>1</sup> Cramer, P; Barrett, C; Lambourne, S & Latham, J (2015). We are still gay ... An evidence based resource exploring the experiences and needs of lesbian, gay, bisexual and trans people living with dementia. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne Australia



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# Information about dementia

**The information in this section defines dementia, describes the symptoms and causes of dementia and explains the difference between memory problems that come with ageing and dementia.**

## What is dementia?

Dementia describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease<sup>2</sup>. Dementia affects thinking, behaviour and the ability to perform everyday tasks. Brain function is affected enough to interfere with the person's normal social or working life.

**The early signs of dementia are very subtle and may not be immediately obvious. Some common symptoms may include:**

- Progressive and frequent memory loss
- Confusion
- Personality change
- Apathy and withdrawal
- Loss of ability to perform everyday tasks

Dementia can happen to anybody and, while it is more common after the age of 65 years, people in their 40s and 50s can also have dementia. In 2019 approximately 447,115 Australians were estimated to be living with dementia<sup>2</sup>.

## What can be done to help?

Learning about dementia and the help available soon after a diagnosis is important. Early support is vital for people living with dementia, and being prepared can help make accessing the services available easier.

The help of care partners, families and friends can also make a positive difference to managing the condition.

Having information about dementia and the supports available to you as a person living with dementia or care partner will make it easier to access the services you want and will assist you to plan for the future.

<sup>2</sup> Dementia Australia (2017) What is Dementia? 10/05/2018: <http://www.dementia.org.au/about-dementia/what-is-dementia>

<sup>3</sup> Dementia Australia Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra

# How can Dementia Australia support me?

**Dementia Australia is committed to the inclusion of people who are LGBTI in all aspects of service provision and offers a wide variety of supports, referrals and services, as well as multilingual resources to all people living with dementia, their care partners, family and friends.**

## Dementia Australia

Services available through Dementia Australia include counselling, support groups, early intervention, education and information.

To find out what Dementia Australia services are available in your area call the National Dementia Helpline on **1800 100 500** or visit the Dementia Australia website at **dementia.org.au**

If you would like to know more about dementia, Dementia Australia's 'What is Dementia?' Help Sheet is a good starting point. The link to this Help Sheet is listed in the Community Resources section of this booklet.

A wide selection of other resources for people who are LGBTI can also be accessed online, or through the National Dementia Helpline on request. You can ask for copies to be mailed out if you do not have access to a computer by calling the National Dementia Helpline on **1800 100 500**



## National Dementia Helpline

The National Dementia Helpline is a free confidential phone and email information and support service that is committed to being LGBTI inclusive. You can call the National Dementia Helpline on **1800 100 500** Monday to Friday during business hours, or you can also get in contact by email: **helpline@dementia.org.au**

Please note in an emergency you should always call **000** for assistance.

### **The National Dementia Helpline provides:**

- Information about dementia and memory loss
- Information about government support services
- Information about services in your area
- Emotional support to help you manage the impact of dementia
- Information on how you may be able to reduce the risk of developing dementia

### **The National Dementia Helpline is for:**

- Anyone interested in dementia
- People concerned about their memory
- People who have been diagnosed with dementia
- Family and friends of people living with dementia
- Care partners who support people living with dementia
- Health or aged care professionals who work with people living with dementia
- Community groups who want to know more about dementia



# How do I access the services I want and need?

**There are two national entry points for people living with dementia, their care partners, family and friends wanting information and access to services.**

## National Disability Insurance Scheme

People living with younger onset dementia who are under the age of 65 can apply for funding through the **National Disability Insurance Scheme (NDIS)** to access services to achieve their goals, maintain their wellbeing and participate in community life<sup>4</sup>.

**Services accessed through the NDIS include<sup>5</sup>:**

- Social support
- Personal and domestic support
- Assistance with transport
- Purchase equipment to support function, mobility, activities of daily living and communication
- Support to participate in community life

For more information about the NDIS, including how to apply and the types of services you may be able to access through the scheme, contact the NDIS on **1800 800 110** or visit the website **[ndis.gov.au](http://ndis.gov.au)**

If you need an interpreter or other assistance call **1800 800 110**. If you are a Text telephone user, call **1800 555 677** and ask for **1800 800 110**.

## Dementia Australia can also support you.

**We offer:**

- Information about the National Disability Insurance Scheme to assist you to apply for funding
- Support Coordination, should this service be included in your NDIS plan

4 & 5 Dementia Australia (2016) Younger Onset Dementia and the NDIS p.7  
10 / 05 / 2017: [www.dementia.org.au/files/resources/yod-and-ndis-booklet.pdf](http://www.dementia.org.au/files/resources/yod-and-ndis-booklet.pdf)

## My Aged Care

My Aged Care is the entry point for people over 65 years who are seeking aged care services, and for some people under 65 years who cannot access the services they need through disability services or the NDIS. My Aged Care provides people with information about aged care services, resources, comprehensive assessment and access to Commonwealth-funded aged care services<sup>6</sup>.

### Services accessed through My Aged Care include:

- Social support
- Respite or permanent residential care
- Personal and domestic support
- Assistance with transport
- Assistance to purchase equipment to support mobility, activities of daily living and communication
- Support to participate in community life

Veterans or war widow/ers who are living with dementia may also be eligible for Department of Veterans' Affairs services. My Aged Care is a good first contact if you would like information about eligibility, how to apply and the services offered.

If you have access to the internet, the 'Aged Care for LGBTI elders: Getting started with My Aged Care' webpage provides useful information about accessing LGBTI inclusive services through My Aged Care. The link to this web page is listed under the Community Resources section of this resource.

If you do not have access to the internet or if you prefer to speak to someone on the telephone, contact **My Aged Care** on **1800 200 422** weekdays between the hours of 8am and 8pm and between 10am and 2pm on Saturdays.

If you need the Translating and Interpreting Service to call **My Aged Care** telephone **131 450** and ask for **1800 200 422**.

<sup>6</sup> Commonwealth of Australia (2018) Need Aged Care Services?  
This is the place to start 09 / 05 / 2017: [www.myagedcare.gov.au/home-start-here](http://www.myagedcare.gov.au/home-start-here)

# I am a care partner, how do I access the services I want and need?

The **Carer Gateway** is for care partners who want access to information and advice, and to connect with services in their local area to support them in their caring role. The Carer Gateway is available through their website and contact centre<sup>7</sup>.

## Information, advice and services accessed through the Carer Gateway include:

- Taking a break (respite)
- Financial help
- Carer support (phone counselling and an online carer forum)
- Carer education (self-guided coaching and skills courses)

The Carer Gateway offers resources for carers who are LGBTI and provides links to a selection of supports for care partners.

The link to the Carer Gateway web page is listed under the Community Resource section of this resource.

You can telephone the **Carer Gateway** on **1800 422 737** Monday to Friday during business hours.



<sup>7</sup> Commonwealth of Australia (2015) Carer Gateway, About Us 07/05/2017: [www.carergateway.gov.au/about-us](http://www.carergateway.gov.au/about-us)

# What do I look for when choosing an LGBTI inclusive service provider?

**This section provides you with tips to help you choose a service provider that is respectful of, and responsive to, the preferences, needs and values of people living with dementia who are LGBTI, their care partners, family and friends.**

## Tips for choosing an LGBTI inclusive service provider

Here are some suggestions about things to look for and questions to ask to help you choose an LGBTI inclusive service provider that is right for you<sup>8 9</sup>.

### Things to look for:

- Familiarise yourself with the provider's services, their policies and costs of care
- Do you feel welcome, respected and safe when you visit or contact the service provider?
- Request the service provider's discrimination policy. Does the policy state clearly that discrimination against people who are LGBTI is not permitted?
- If you are looking at an aged care facility - does it offer a private area that you can use if you want to be alone with your partner, friends and family?
- Do the brochures and other written material published by the service provider use LGBTI inclusive language?
- Do the photographs in their marketing materials depict diverse relationships and sex or gender identities?

### Questions to ask:

- Ask the service provider if their staff have access to and attend training about LGBTI inclusive practice and cultural safety
- Ask people you know if they are familiar with the service provider and what they think of it
- Ask the service provider if they have a policy to support relationships that are important to you, including your relationship with your partner, friends or family members
- Ask the service provider if the service recognises and celebrates occasions that may be important to you as a person who is LGBTI, such as the Sydney Gay and Lesbian Mardi Gras or the Coming Out Ball in Melbourne
- Ask for copies of their client record documents. Do they provide LGBTI inclusive options that support your identity and relationships?

Trust your judgement about whether a service provider will be right for you, your partner, or the person you are supporting.

One way to find an LGBTI inclusive service provider is to look for services that display the Rainbow Tick.

The **Rainbow Tick Standards** are a set of six quality standards against which service providers can choose to be audited to demonstrate that they are LGBTI inclusive. They were developed by GLHV (formerly known as Gay and Lesbian Health Victoria), in collaboration with QIP (Quality, Innovation and Performance), an organisation responsible for accreditation and certification of quality standards for health and community service organisations.

Some service providers choose to undertake a quality audit against the Rainbow Tick Standards, and if they successfully meet all the standards, they are permitted to display the Rainbow Tick in the National Disability Insurance Scheme, My Aged Care, and Carer Gateway service finders and can visibly demonstrate that they are LGBTI inclusive.

It is important to note that the Rainbow Tick Standards are optional for service providers and that the Rainbow Tick is not the sole measure of LGBTI inclusive practice.

The link for the Rainbow Tick Standards website is listed in the Community Resources section of this resource.

8 Alzheimer's Australia (2014) LGBTI People and Dementia: the important issues p.5 20/04/2017: [www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf](http://www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf)

9 Silver Rainbow Project (2016) Choosing an LGBTI Inclusive Ageing & Aged Care Service Australia. National LGBTI Health Alliance 07/03/2017 <https://lgbtihealth.org.au/wp-content/uploads/2016/07/Silver-Rainbow-FACT-SHEET-1.pdf>

# What happens if I need help to make decisions or want a friend or family member to speak for me?

By planning ahead, discussing your wishes with your care partner and close friends and appointing someone, or more than one person, to make decisions for you if are not able to do so yourself, you can have peace of mind that your preferences will be communicated to service providers and your wishes will be legally respected<sup>10</sup>.

Planning ahead may also be called Advance Care Planning.

Two helpful resources about planning ahead are the Dementia and Your Legal Rights guide and Dementia Australia's Planning Ahead resources. These two resources are discussed below.

## Dementia and Your Legal Rights

**Dementia and Your Legal Rights** is a practical guide, developed by Dementia Australia, that sets out some of the legal issues a person living with dementia, their care partners, families and friends may face. It also outlines how to plan ahead, legal rights and the actions people can take to protect their rights.

The website link for the Dementia and Your Legal Rights guide is listed in the Community Resources section of this booklet. To request a hard copy of this resource call the National Dementia Helpline on **1800 100 500**.

## Planning Ahead

**Planning Ahead** is a suite of information and worksheet resources that cover all aspects of future planning including financial and healthcare issues, advance care directions and general statements about your values, wishes and preferences.

**Planning Ahead resources are useful for:**

- People with early signs of memory loss or dementia
- Care partners of a person with loss of capacity because of dementia or another condition

The link for the Planning Ahead tools is listed in the Community Resources section of this booklet. If you would prefer to talk to with someone about planning ahead, call the National Dementia Helpline on **1800 100 500**.

<sup>10</sup> Alzheimer's Australia (2016) Dementia and Your Legal Rights p.4



# How do I resolve issues or concerns I have about the care I or someone close to me receives?

**People living with dementia who are LGBTI, their care partners, family and friends have the right to receive high quality services from staff who are respectful and appropriately trained<sup>11</sup>.**

## What if I have a complaint about the care I receive from my aged care service provider?

If you receive an aged care service and you wish to raise an issue or make a complaint about the care provided, you should first approach your service provider to raise your concerns.

If you receive a Commonwealth-funded aged care service and you are not able to have your complaint heard or addressed to your satisfaction by your service provider, you can ask the Aged Care Quality and Safety Commission to work with you and the service provider to review and resolve your complaint.

You can find out more about the role of the **Aged Care Quality and Safety Commission**, how to make a complaint and lodge your complaint by calling **1800 951 822**.

## What if I would like support to talk with my aged care service provider and lodge my complaint? Is there anyone who can support me?

The Older Persons Advocacy Network is funded to support older people, their care partners, families and friends to address concerns they may have about Commonwealth-funded aged care services. The Network acts as an independent advocate and can support you to speak with your service provider about your concerns or to lodge a complaint with the Aged Care Quality and Safety Commission.

You can find out more about the support offered by the **Older Persons Advocacy Network** by calling **1800 700 600**.

<sup>11</sup> Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 Explanatory Memorandum (Cth)



## What if I have a complaint about my National Disability Insurance Scheme (NDIS) funded service?

If you receive a NDIS funded service and you have a concern about the care you receive, you should first raise your concern with your service provider.

If discussing your concern with your service provider is difficult for you to do, or if your concern is not resolved to your satisfaction, you may be able to get support to raise your concern with your service provider.

## Who do I contact if I need support to raise a concern with my National Disability Insurance Scheme service provider?

The NDIS Quality and Safeguards Commission (NDIS Commission) provides a complaints mechanism for people who receive National Disability Insurance Scheme funded services.

The NDIS Commission is operational in all states and territories except Western Australia. You can make a complaint to the NDIS Commission by calling **1800 035 544** (free call from landlines).

If you live in Western Australia, you can make a complaint to the Health and Disability Services Complaints Office (HaDSCO) by calling **1800 813 583**.

## How is the privacy and confidentiality of people who are LGBTI protected?

You do not have to disclose that you, your family member, or the person you care for is a person who is LGBTI to health, disability or aged care providers or staff<sup>12</sup>.

That a person is LGBTI is private and confidential and providers and staff cannot share this information without consent<sup>13</sup>.

You have the right to request the name, gender and pronouns (if any) that are used to address you<sup>14</sup>.

If you want more information about how privacy is protected or to report a breach of privacy you can telephone the **Office of the Australian Information Commissioner** on **1300 363 992**.



12 Alzheimer's Australia (2014) LGBTI People and Dementia: the important issues p.6 20/04/2017: [www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf](http://www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf)

13 Alzheimer's Australia (2014) LGBTI People and Dementia: the important issues p.6 20/04/2017: [www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf](http://www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf)

14 Alzheimer's Australia (2014) LGBTI People and Dementia: the important issues p.6 20/04/2017: [www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf](http://www.dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf)

# How are the rights of people who are LGBTI protected?

In Australia, the Sex Discrimination Act (1994) protects the right of people who are LGBTI to access appropriate, non-discriminatory services, and to be treated with dignity and respect<sup>15</sup>.

If you believe that you are being discriminated against because of your sexual orientation, gender identity or intersex status, you can lodge a complaint in writing with the Australian Human Rights Commission.

To request a hard copy of the complaint form or if you need assistance and support to lodge your complaint, you can call the **Australian Human Rights Commission** on **1300 656 419**.



<sup>15</sup> Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 Explanatory Memorandum (Cth)

# Who do I contact if I want information about dementia that was not included in this resource?

Dementia Australia is the peak non-profit organisation for people living with dementia, their care partners, families and friends.

We represent all Australians living with dementia (currently estimated at more than 447,115) and more than 1.2 million people involved in their care.

Dementia Australia works with individuals and families, all levels of government, and other key stakeholders to ensure that people of all ages with all types of dementia, their families and carer partners are appropriately supported – at work, at home (including residential aged care) and in their local community.

In addition to advocating for the needs of people living with all types of dementia, their families and carer partners, Dementia Australia provides support services, education and information aimed at addressing the gaps in mainstream services.

Dementia Australia is committed to LGBTI inclusive practice and welcomes enquiries from people living with dementia who are LGBTI, their care partners, families and friends. If you have questions or would like information on a topic not discussed in this resource, contact the National Dementia Helpline during business hours on **1800 100 500**

You can also contact the National Dementia Helpline by email at **[helpline@dementia.org.au](mailto:helpline@dementia.org.au)**

# Community Resources

Aged Care for LGBTI elders: Getting started with My Aged Care: [agedcare.health.gov.au/support-services/my-aged-care/aged-care-for-lgbti-elders-getting-started-with-my-aged-care](https://agedcare.health.gov.au/support-services/my-aged-care/aged-care-for-lgbti-elders-getting-started-with-my-aged-care)

Dementia and Your Legal Rights Guide: [dementia.org.au/resources/dementia-and-your-legal-rights](https://dementia.org.au/resources/dementia-and-your-legal-rights)

Carer Gateway: Resources for carers who are LGBTI [carergateway.gov.au/resources-for-lesbian-gay-bisexual-transgender-intersex-carers](https://carergateway.gov.au/resources-for-lesbian-gay-bisexual-transgender-intersex-carers)

Rainbow Tick Standards: [glhv.org.au/lgbti-inclusive-practice](https://glhv.org.au/lgbti-inclusive-practice)

Planning Ahead tools: [dementia.org.au/planning-ahead](https://dementia.org.au/planning-ahead)

What is Dementia? Help Sheet website link: [dementia.org.au/files/helpsheets/Helpsheet-AboutDementia01-WhatsDementia\\_english.pdf](https://dementia.org.au/files/helpsheets/Helpsheet-AboutDementia01-WhatsDementia_english.pdf)

# Additional Resources

**Here are two national organisations that are useful for people who are LGBTI.**

**National LGBTI Health Alliance** is the national health peak body that provides LGBTI and other gender and sexuality diverse health programs, services and research to people who are LGBTI.

Website: [lgbtihealth.org.au](https://lgbtihealth.org.au)

Telephone: **02 8568 1123**

**QLife** is a national advocacy, counselling and referral service for people who are LGBTI.

Telephone: **1800 184 527** or choose the chat tab on the QLife website.

Website: [qlife.org.au](https://qlife.org.au)

Telephone counselling and chat are available from 3pm to midnight every day.

# References

Alzheimer's Australia (2016) **Dementia and Your Legal Rights**

Alzheimer's Australia (2014) **LGBTI People and Dementia: the important issues** p.5  
20/04/2017: [dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf](https://dementia.org.au/files/SA/documents/LGBTI%20People%20and%20Dementia%20Booklet%20-%2020150112.pdf)

Commonwealth of Australia (2015) **Carer Gateway, About Us** 07/05/2017:  
[carergateway.gov.au/about-us](https://carergateway.gov.au/about-us)

Commonwealth of Australia (2018) **Need Aged Care Services? This is the place to start**  
09/05/2017: [myagedcare.gov.au/home-start-here](https://myagedcare.gov.au/home-start-here)

Crameri, P; Barrett, C; Lambourne, S & Latham, J (2015). We are still gay... An evidence based resource exploring the experiences and needs of lesbian, gay, bisexual and trans people living with dementia. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne Australia

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[dementia.org.au/about-dementia/what-is-dementia](https://dementia.org.au/about-dementia/what-is-dementia)

Dementia Australia (2016) **Younger Onset Dementia and the NDIS** 10/05/2017:  
[dementia.org.au/files/resources/yod-and-ndis-booklet.pdf](https://dementia.org.au/files/resources/yod-and-ndis-booklet.pdf)

Dementia Australia **Dementia Prevalence Data 2018-2058**, commissioned research undertaken by NATSEM, University of Canberra

**Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Bill 2013 Explanatory Memorandum (Cth)**

Silver Rainbow Project (2016) **Choosing an LGBTI Inclusive Ageing & Aged Care Service Australia**. National LGBTI Health Alliance 07/03/2017:  
[lgbtihealth.org.au/wp-content/uploads/2016/07/Silver-Rainbow-FACT-SHEET-1.pdf](https://lgbtihealth.org.au/wp-content/uploads/2016/07/Silver-Rainbow-FACT-SHEET-1.pdf)

**dementia.org.au**

National Dementia Helpline 1800 100 500



For language assistance  
call **131 450**