

CARING FOR LGBTI PEOPLE WITH DEMENTIA

A GUIDE FOR HEALTH AND AGED CARE PROFESSIONALS



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SAVE AUSTRALIA**
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**LESBIAN, GAY, BISEXUAL,
TRANSGENDER AND INTERSEX
(LGBTI) PEOPLE WITH DEMENTIA,
AND THEIR CARERS, PARTNERS,
FRIENDS AND RELATIVES, FACE
MANY CHALLENGES, NOT ONLY
THE CHALLENGES THAT OTHER
PEOPLE FACE IN THIS SITUATION
BUT POSSIBLY MANY MORE.
THIS BOOKLET WILL HELP HEALTH
AND AGED CARE PROFESSIONALS
UNDERSTAND SOME OF THE
ISSUES THAT LGBTI PEOPLE
MAY FACE AND HOW TO OFFER
APPROPRIATE SUPPORT.**

UNDERSTAND

HOW MANY LGBTI PEOPLE?

By the year 2050, it is estimated that nearly 1 million people in Australia¹ will be living with dementia. As LGBTI people are estimated to make up 11% of the Australian general population, that means there will be approximately 100,000 LGBTI people with dementia by that date.² This does not count the many more LGBTI people who will be caring for others with dementia or who are the friends or relatives of people with dementia.

DON'T THINK YOU WILL HAVE CONTACT WITH LGBTI PEOPLE?

It is possible because LGBTI people are a minority group. However, it is more likely that you will have contact with LGBTI people or have already but did not know because they were reluctant to disclose their sexual orientation, gender identity or intersex status.

HISTORY AND EXPERIENCE OF DISCRIMINATION

The vast majority of older LGBTI people have experienced a lifetime of rejection, stigma, discrimination and abuse, not only from the community at large but also from their own families and from legal, medical and health care systems.

Because of this shared history of discrimination and abuse, many older LGBTI people have felt forced to live lives of social and sexual invisibility, hiding their most important relationships and, as a result, experiencing a negative impact on their health and wellbeing.

For those older LGBTI people who have lived more openly, many are now concerned about the threat to their safety from the increased dependence on others, especially service providers. They do not feel confident these support services will be able or willing to meet or understand their specific needs. Many are wondering if they should go back to hiding that they are LGBTI?

There are many things you can do that will help to make your service safe, welcoming and inclusive for LGBTI people.



AWARENESS OF LGBTI HEALTH ISSUES

Being part of a stigmatised and discriminated against minority group is not good for your health. Studies have shown that LGBTI people have a higher incidence of psychological distress and are more likely to have considered or have attempted suicide than the general population. They are more likely to be current smokers. They are also more likely to have been homeless and to have used illicit drugs.³

These health impacts are not because they are LGBTI, but because of how they are regarded and treated, and sometimes because they have even come to believe the negative things said about them.

For many LGBTI people, especially transgender and intersex people, the need for medical treatment and personal care services (showering, dressing and undressing) can be a cause of great anxiety – because people will know they are LGBTI. Their fear is that they will receive inadequate treatment, be denied services or face other forms of discrimination or prejudice once it is known they are LGBTI.

As a result of this, over their lifetime, LGBTI people may have accessed routine health care checks and screenings less often than other people. Keep this in mind when assessing their needs. They may have undiagnosed pre-existing conditions.

Hormone therapy may be used by both transgender people and intersex people over the course of their life. This is something that hospitals and residential care facilities need to be aware of because while there may be health risks (cancer and cardiovascular disease) linked to prolonged hormone use. The sudden cessation of hormones can also increase depression and in some cases lead to suicidal feelings.

For those transgender people who have had various forms of cosmetic surgery or gender affirmation surgery, there may be health needs linked to these procedures.

Trans men (female to male) using hormone therapy who have not had a complete hysterectomy are at increased risk of endometrial and ovarian cancer. Therefore screening for cervical cancer remains important. Breast cancer screening is also still important too even if breast tissue has been removed. Similarly, for trans women (male to female), screening for breast and prostate cancer is recommended.

THE LANGUAGE AND WORDS YOU USE MATTER

Take your cue from the people themselves as to the kind of language you should use to talk about or refer to an LGBTI person.

For example, some LGBTI people refer to themselves as 'queer' but may not be comfortable with you doing so. For other LGBTI people, 'queer' is a derogatory term.

Older women may refer to themselves as 'gay' and not 'lesbian'.

A partner or boyfriend/girlfriend may be referred to only as 'my companion' or 'my friend'.

A trans man who has transitioned to being female and has adopted the style and presentation of a woman will expect to be referred to as 'she' no matter what their birth certificate says or what their body looks like.

DECIDING TO TELL SOMEONE YOU ARE LGBTI

Over the course of their lives, and often several times daily, many LGBTI people will be weighing up whether it is safe for them to tell this or that person that they are LGBTI. Imagine the stress this produces. Imagine what impact feeling you have to conceal something so fundamental about yourself has on your relationships with other people.

INADVERTENT DISCLOSURE

In some situations, an LGBTI person's sexual orientation, gender identity or intersex status may be revealed without them actually wanting this to happen. Their medical records may reveal it, or because of the reduced inhibition that is sometimes caused by dementia, they may inadvertently let it be known. This makes it even more important for them to be in a safe and non-judgmental environment. It is as important to ensure that care workers supporting the person are not homophobic or transphobic (displaying fear or contempt for LGBTI people) as it would be to ensure that they are not racist or sexist.

I THINK MY CLIENT/RESIDENT IS LGBTI

If you think that someone is LGBTI, try to offer positive messages in subtle ways. For example, if someone is living with someone of the same sex and you think it may be a gay relationship, you might say, *'You obviously mean a lot to each other'* or *'Have you lived together a long time?'* These kinds of questions do not compel someone to say they are LGBTI ('come out') if they don't want to, but they do give an opening, indicating that you are happy to talk about the relationship.

MY CLIENT/RESIDENT HAS JUST TOLD ME THEY ARE LGBTI

If the person with dementia or their carer tells you that they are LGBTI, your first and immediate reaction or response will be very important. If you look embarrassed or shocked, change the subject or avoid direct acknowledgement of what the person has shared with you, it might stop the person feeling comfortable with you and opening up further. Find ways to acknowledge the person's sexual orientation, gender identity or intersex status and give reassurance that you are not prejudiced. For example, you might say something like:

"Thank you for telling me. It must be hard having different professionals coming into your house, not knowing what their attitudes are,"

or,

"Thank you for telling me. Let me know if there are any particular things we need to consider about services for you, which might make you feel more comfortable".

Check out, too, who else knows or is not to know. There may be members of their family or personal contacts network who do not know or are not to know.

I'M LGBTI TOO

If you are LGBTI yourself, you will need to consider whether it is appropriate to 'come out' to your client and/or their carer. Professional boundaries have traditionally dictated that revealing personal information is not good practice. However, in some situations, and where you are confident and open about your own sexual orientation, gender identity or intersex status in the workplace, it might be entirely appropriate to reassure your client that, as a fellow LGBTI person, you might be able to offer empathy and support at a difficult time.

If you are not LGBTI, and have had little contact with LGBTI people, consider the extent to which you need to equip yourself with more information. You may also need to carry out further informal research into specialist sources of support for an LGBTI person with dementia and their carer. You could use the Internet to contact local LGBTI self-help or support organisations to find out more about what is available.

BE AWARE OF ASSUMPTIONS

Just because someone has never married does not mean they have never had an intimate or important lifetime partnership. Of course, this does not automatically mean that they are LGBTI either. Be aware that a person may have had important relationships that can go unnoticed when they get older simply because they have not been legitimised by a marriage.

BE AWARE OF THE DIFFERENCES BUT RESPOND TO THE WHOLE PERSON

The lived experiences of LGBTI people have often been very different from those of other people. The people they talk about, the memories that are important, their interests and their humour all will have been shaped by these life experiences.

Be mindful, too, that being LGBTI is just one part of who people are. Their unique needs must be acknowledged, but you need to see and respond to the whole person.

ONE SIZE DOES NOT FIT ALL

LGBTI people are not a homogenous group and there is no one LGBTI community. Be mindful of the differences between people. The two LGBTI people in a day care or residential care facility are not necessarily going to want to be friends or even like each other. Your LGBTI client or resident is not necessarily going to want an LGBTI staff member to care for them.

Some LGBTI people will have lived their entire lives with virtually no contact with other LGBTI people.

For others, having regular contact with other LGBTI people and events or activities has always been and will continue to be important to support their identity and confidence, especially in times of loss or change. You can use the internet to find out about local LGBTI support groups.

BEING THE ONLY ONE

Think about a time when you felt like an outsider in a group. Remember how lonely and isolating it was. What must it feel like then to be the only LGBTI person in a group? You are in the spotlight whether or not you want to be.

Then again, what must it be like to feel the need to hide something so important about yourself and to be constantly on guard so as not to let it slip. What must it feel like to be fearful of reminiscing with others about your life and family in case they are offended or appalled?

Older LGBTI people may feel out of place in traditional day care, lifestyle programs and support groups. LGBTI people may fear that others will react with shock, awkwardness or even rudeness if they talk about their lives and relationships. They may need your help to be accepted. They may need you to look at how you can modify your groups or activities so as to include all people.

FAMILY MATTERS

Older LGBTI people are more likely to be single and more likely to live on their own. They are also much less likely to have children or regularly see family members. If people do not have a partner or family to support them as they get older, they are more likely to need health and aged care services.

You may hear the phrase 'chosen family' used in relation to some LGBTI people. If their relationships with their birth families have become fractured as a result of them being LGBTI, they may now rely on a 'chosen family' made up of partner, ex-partners and friends. Chosen families can provide a strong base of support.

CONCERNING OR OUT OF CHARACTER BEHAVIOUR

Dementia can also cause some people to display out of character and inappropriate sexual behaviours. This can happen whether or not the person is LGBTI. It is not about them being LGBTI, it is about dementia.

Advice on dealing with these behaviours of concern can be obtained from the **Dementia Behaviour Management Advisory Service (DBMAS)** on 1800 699 799.



THE IMPORTANCE OF PLANNING FOR THE FUTURE

It is especially important for LGBTI people with dementia to have financial, legal and medical documents in place to protect their interests and detail their wishes for care as the disease progresses. Depending on the state or territory, an Advanced Care Directive, Enduring Power of Attorney, Enduring Power of Guardianship or Medical Power of Attorney and a valid Will need to be put in place while the person is still considered legally competent to make such decisions.

Making their wishes known about funeral arrangements is important for LGBTI people, too. For example, someone who has transitioned from male to female will want to be buried as female. Transgender people often fear that family not accepting of them will take over and they will be buried as their birth sex and name.

By encouraging this kind of planning ahead, you can help ensure that the person with dementia will have their wishes carried out until end of life. It will also ensure that their partner, carer or significant other will have the level of access and authority in the care planning process desired by both them and the person with dementia.

Encourage carers, partners or significant others to do this forward planning as well. What do they want to happen to ensure the person with dementia will be cared for appropriately in the event of something happening to them?

Older LGBTI people worry that their partner or chosen family, those they rely on, will be excluded from the care process because health professionals do not see them as real family. You can refer them to the **Start2Talk website (www.start2talk.org.au)** for information and help to do important forward planning.

CARING AS WELL

Remember, LGBTI people will not only be your clients or residents but also the carers, friends, visitors and relatives of other people with dementia including some who are not LGBTI, maybe even their parents.

WHAT DOES YOUR PAPERWORK SAY ABOUT YOU?

Review your publicity material, intake and admission forms and processes, and policy documents. Make sure that the language used is inclusive of LGBTI people, including those not in heterosexual partnerships. If pictures or photographs are used, think about including some images of LGBTI people.

Intake forms need to allow clients or residents to say 'partnered' or 'married.'

Questions about sex, sexual orientation, gender identity and intersex status should be asked routinely of all clients or residents.

ACCOMMODATION OPTIONS

If your service segregates people according to sex the decision should be based on the person's gender identity and not their assigned at birth sex.

MEASURE OF SUCCESS

Remember, the measure of your success or your organisation's success is not that LGBTI people disclose to you. It is that you can say with confidence that you offer a safe and inclusive setting in which some could choose to disclose.

ANTI-DISCRIMINATION LEGISLATION

In Australia, under the Sex Discrimination Act, 1984, it is unlawful to treat people unfairly because of their sex, sexual orientation, gender identity or intersex status. This means that service providers have a duty to ensure that their services and their staff do not discriminate against people on any of these grounds and that they are inclusive of LGBTI people.

REFERENCES

1. *Access Economics (2009) Making choices, Future Dementia Care: Projections, Problems and Preferences. Report for Alzheimer's Australia.*
2. *Department of Health and Ageing, Commonwealth of Australia, Canberra. 2012. National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy.*
3. *Australian Bureau of Statistics (2007), "National Survey of Mental Health and Wellbeing" Additional unpublished analysis] Extract from Press Release: "LGBTI Community Left Out of Health Reform" (National LGBT Health Alliance, April 2010).*

FURTHER INFORMATION

For details of Alzheimer's Australia locations and services in your state and for information about a wider range of dementia related topics, visit:
www.fightdementia.org.au

CONTACT US

National Dementia Helpline
1800 100 500 (Office hours only)

The National Dementia Helpline is an initiative of Australian Government

DBMAS

The Dementia Behaviour Management Advisory Services
1800 699 799 (24 HOURS)

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