



INTERACTING WITH LGBT+ PEOPLE LIVING WITH DEMENTIA

There are resources and training available to help understand dementia and the kinds of changes people living with dementia experience.

There are over 100 diseases that can cause dementia.

The most important thing to remember is that people living with dementia are still people with histories, feelings, likes and dislikes. Getting to know about the person you visit is a key



to supporting connection – just as it is with any friend or acquaintance.

The person living with dementia is not disappearing, but you might need to work harder to discover who they are and what they need as their dementia progresses.

People living with dementia might do things or act in ways that change over time. This might take some getting used to.

The main thing is, don't say 'Remember...'

Gwenda Darling, pansexual person
living with dementia

YOU MIGHT WANT TO TRY THESE THINGS

If someone is repeating stories

Use tact and patience – avoid saying, 'I remember,' 'You've told me that before' or 'I know'.

Enjoy the story and ask questions to help them uncover new or additional details, particularly if you know the details of the story.

If someone is repeating questions or appears anxious:

Help them find the answer themselves, support them in finding an answer. *For example, if they are asking the time, suggest moving a clock into a more visible area.*

› Offer reassurance.

› Do something that they find calming.

If someone forgets who you are

Always introduce yourself with warmth when you visit. Your familiarity and warmth helps the person you visit feel safe. It's not personal, but can be sad and disheartening, especially if you have developed a strong friendship. Even if someone can't remember who you are, you are still very important.

Expect there may be changes in how they greet you or feel about you from visit to visit. Expect that sometimes they might think you are someone else.

If someone is restless – (e.g. pacing, fidgeting)

Support them in an outing or walk if appropriate.

› Introduce activities that use their hands. *For example, drawing, painting, worry beads or handling items that mean something to them.*

› Offer to sit down for a cup of tea or coffee together.



If someone is losing confidence and is increasingly anxious, stressed or withdrawn

If someone finds you offering them options for activities overwhelming, it can help to frame things as positive statements. *For example, 'Now's a good time to go for our walk.'*



💡 Consider planning a few simple activities to offer the person you visit before you get there so you have some ideas ready. ➤ The Visiting Guide has some suggestions about what this might involve.

➤ Listen to their feelings about anxiety and stress. There are few people who will take the time or have the time to listen to them. Sometimes there may be things that you will need to report to the coordinator or the staff about their concerns.

➤ Ask them for help with simple tasks that they feel confident in and have previously enjoyed, for example setting out a snack, watering a plant or a craft activity

➤ Offer a snack or drink.

➤ Break tasks down into small steps. They may not be able to do all the steps but can do some.

💡 If someone is following you around or wanting to leave:

Sometimes people living with dementia may follow you around or want to leave the environment they're in because they don't recognise where they are as home. It can help to ensure that they have familiar things around them, and to offer reassurance that they are in a safe place.

For example, 'You are in a safe place where you live now. I'm here for another hour and we're going to [go for a walk/ paint/listen to music] before I go.'

➤ Consider activities where they can be side-by-side with you, such as reading, viewing a movie or making something.

💡 If someone is using less speech, being abrupt or not using speech to communicate:


Even when someone does not use speech, they may still be able to understand speech and will respond to how you speak, your tone and body language.

Observing and responding to body language and gesture, and reassuring touch may help some people.


For example, you might take along some hand cream and say, 'Oh look, I've got some hand cream here. I'm putting it on my hands because it smells of lavender. Would you like me to rub some into your hands? I'm going to rub some into your hands now.'

➤ Re-tell stories they have told you before or talk about things you have done before. Continue to do activities together that you have always done.



 **Bring photos and other visuals and objects that can support you to communicate and engage.**

› You could also reach out to the lifestyle coordinator if they are in a residential aged care facility to see what activities they have and if the person is interested in anything in particular.

 **If someone is engaging in sexualised behaviours, such as flirting with you or others, taking off their clothes or talking about sexual activities. This is called disinhibition which can occur with certain types of dementia. It is not personal.**

Even though you might find the situation embarrassing and confronting, a quiet, calm and gentle response can help to defuse the situation. *For example, 'It's time to get dressed in your best clothes now so that we can go for a coffee' or 'I have some activities for us to do.'*

EXPRESSION OF GENDER AND SEXUALITY

Living with dementia can change people's expression of and communication about their gender and/or sexuality.

This can mean that people who were not previously 'out' may become more open about expressing their gender and/or sexuality. Sometimes it will mean that people's gender expression is more fluid (e.g., dressing, presenting or speaking differently, depending on the day).

For example, a transgender woman living with dementia in aged care may grow her facial hair because she has found it increasingly intense and difficult to have care staff shaving her. This does not mean that she is not still wanting to be recognised in her gender identity as a woman.



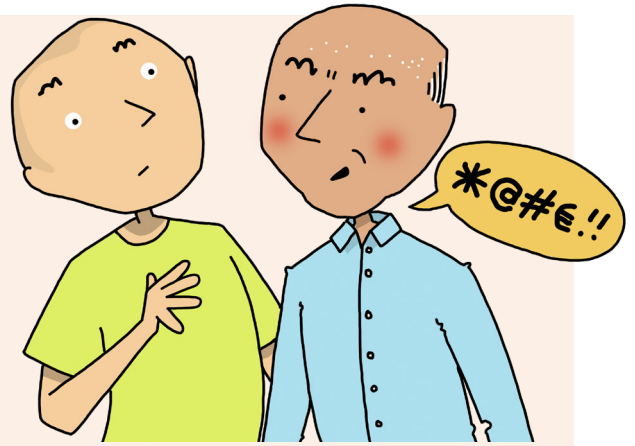
WHAT TO TRY

Respect the person living with dementia's choices around their gender expression and disclosure. Choose activities that affirm their gender expression on the day of a visit.



They would express their gender more freely when they were hanging out with me.

Beau



IF SOMEONE SEEMS AGGRESSIVE.

For example, is shouting, throwing things, making threats or pushing or hitting

Even though this can be confronting, it's important to stay calm and not argue or disagree with someone. These kind of behaviours can be masking someone's pain, discomfort or frustration, so it is essential that you let someone else know when this happens. A sudden change in someone's behaviour from how they normally are can be a sign that there is something medically wrong such as an infection, so it is important to report any changes you notice in the person you are supporting.



Ensure your own safety in a high risk situation.

For example, leave the room and come back later when they have calmed down. If possible, encourage the person to go to a safe environment where there is less stimulation and fewer people. Be sure to report this to the coordinator and the aged care staff in the person lives in a facility.

THINGS THAT CAN BE SPECIFIC TO LGBT+ COMMUNITIES

If you identify as gender and/or sexuality diverse yourself, there are some particular challenges you might face visiting LGBT+ people living with dementia.

Many of these challenges come from a strength: that you have built a strong relationship with the person you visit.

This connection is often the only one that the person living with dementia has, which can make your role even more significant and important.

DISINHIBITIONS

Dementia can impact someone's inhibitions. This means that someone may say or do things that are out of character or rude.

This can result in them acting in ways that are particularly difficult for LGBT+ visitors, such as:

- › Stating racist, homophobic or transphobic views
- › Recounting details about their sexual lives or interests
- › Acting in sexualised ways specific to LGBTI+ visitors
- › Recounting traumatic events from their past, particularly those related to discrimination, violence and trauma around their gender and/or sexuality.

WHAT TO TRY

Remember disinhibition is not a deliberate attempt to hurt you, but a part of living for some people with dementia.

Contextualise the person living with dementia's attitudes in terms of their history. They grew up in a time when gender and/or sexuality diversity was seen as abnormal and criminalised.

Respond with patience.

Sometimes you might be able to explain, for example, 'that word makes me upset' or 'this story makes me feel uncomfortable'.

Re-direct someone with another affirming activity or story that can lead you to safer ground.



In the case of the person recounting traumatic events you should report it to a safe person, perhaps a coordinator, particularly if the violence has occurred more recently or in a care environment.



Explaining LGBT+ Acronym

In these resources we use the acronym LGBT+ to refer to lesbian, gay, bisexual and transgender people. We acknowledge that gender and/or sexuality diversity encompasses a greater range of forms and expressions of diversity than can be captured in the LGBT+ acronym.

We nonetheless have chosen to use this acronym in this resource because there is no published peer-reviewed research currently available on the experiences of intersex or asexual people living with dementia.

While these resources may be useful for broader communities, they have only been informed by our own research and that of others documenting the experiences of people living with dementia who identify as LGBT+. We also do not use the word 'queer', because it remains a complex and potentially hurtful term for many older LGBT+ people, because of its historic use as a demeaning slur.

Co-design process

The development of this resource was led by Dr. Louisa Smith at Deakin University. This resource was co-designed with six people who had visited LGBT+ people living with dementia over an extended period of time.

A Reference Group was also consulted at each step of the co-design process, providing input into the resources.

The Reference Group included LGBT+ people living with dementia and their carers and representatives from LGBTQIA+ organisations and dementia care organisations.

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