

Dementia, Care and Elderly LGBT people.

At the 2021 Alzheimer's Association International Conference (AAIC) in Colorado data revealed 1 in 6 trans people compared to 1 in 10 cisgender people are more likely to experience worsening memory or thinking. What makes understanding the needs of LGBT people living with dementia even more difficult is because of minimal literature in the field of ageing and dementia. Studies suggest older trans people who have not had gender reassignment surgery are particularly vulnerable because others may assume they are not trans or have de-transitioned because of dementia. Studies also suggest that organisations adopting the philosophy, "We treat everybody the same" may not even consider their LGBT service user needs.

Case Studies

Consider the experience of Edna, dementia resulted her loss of capacity to self-advocate and educate staff about her needs. She was vulnerable to transphobia from her family. Eve forgot she had transitioned and became physically and verbally upset with the fact that she was wearing female clothes. She expressed both curiosity and distress regarding her breast implants. How would you manage this situation?

Dementia Issues and risks

There are risks that some Trans People Living With Dementia (TPLWD) may forget health screening i.e. prostate & breast checks. TPLWD who have transitioned earlier in life could become invisible due to the longevity of transition, losing ability to self-advocate because of dementia, and recognise invisible health issues. For Trans men it may include side effects associated with testosterone therapy. Transwomen may experience long-term effects of oestrogen replacement therapy, such as increased liver test abnormalities or blood Clots.

Carers need to be aware that Trans woman who have had surgery may require dilation and douching support if they have had Gender reassignment surgery. They may also need prostate checks A Trans man may still need cervical smear tests.

Legal and ethical considerations.

Legislation gives LGBT people certain rights, which you cannot overlook. Once a trans person has a Gender Recognition Certificate (GRC) they must be treated in their affirmed gender for legal purposes. This means you must consider how you share information concerning their trans identity as it should be confidential, and disclosure without permission could potentially mean you will break the law. It is not okay to "out" an LGBT person without their express permission, even if you think as a carer you have a right to do so. That is why planning is so important.

Planning and giving LGBT people autonomy

The role of Advanced statements, living wills, Gender or Health Passports - saves continual 'Coming Out'. They provide key information on a 'need to know' basis, and counter potential breaches of privacy/law such as GDPR and the Gender Recognition act. A record of what is important to the service user may help to make care planning easier.

Health Passports for TPLWD - Pros and Cons

If you plan to use health passports, recognise their limitations. In a study involving 28 participants-(service user, carers and family) they considered the passport to be unnecessary at the early stage of their healthcare. Several families did not want to share personal details with doctors. Some did not acknowledge the relevance of the passport or its usefulness. Caregivers found healthcare demands overshadowed its use. Family caregivers mainly took responsibility for holding People Living with Dementia (PLWD) from using it. Carers sometimes 'self-censored' information, believing doctors were unlikely to read it, perceived that clinicians might see it as a burden and did 'not want to bother' them.

Health Passports and building trust.

Research suggests end of life planning using legal documents must be fluidly integrated into the lived experience of PLWD because it respects autonomy. Recognise that by asking people to secure their rights through end-of-life documents you are not making an ableist/sanist/cognitivist assumption the pre-dementia self is better suited to making decisions than the PLWD.

Avoid assumptions

Do not assume a LGBT person Living with Dementia wants to disclose their sexuality or gender identity to you. Particularly if they do not trust you. What are the messages that you, or your organisation give out? Do you explicitly say through your words, actions or advertising material that you support LGBT people? "Coming out" can be a lifelong experience for LGBT people and is not easy experience. Just because you assume you treat everybody the same, how do you demonstrate this?

Conclusion

Successful LGBT dementia care relies on good relations between the service user, staff, managers, family members and other service users. Adopting a "We treat everybody the same" approach risks overlooking LGBT peoples psychological and

physical health needs. Instead treating everybody FAIRLY. Turn over to assess how inclusive you really are!





Getting started: checklist for good practice.

This checklist follows a format devised by Dementia Care Matters, to enable organisations to appraise themselves and identify action areas on which to focus. (Age UK, 2015). Check your personal awareness and commitment

Demonstrating personal awareness and commitment	Yes	No	Partly
1. Being open and honest: I start by acknowledging my own attitudes to lesbian, gay, bisexual and trans people and that no one is without bias and preconception.			
2. Acquiring knowledge: I try to make time to find out more by reading or talking to people who are knowledgeable about lesbian, gay, bisexual or trans issues.			
3. Responding to prejudice: I try to challenge prejudiced or discriminatory comments rather than letting them pass.			
4. Avoiding assumptions: I try not to make assumptions about someone's sexual orientation or gender identity.			
5. Valuing shared confidence: if someone tells me they are lesbian, gay, bisexual or trans, I understand it is important to acknowledge and value what has been shared.			
6. Gaining permission: I respect someone's sexual orientation or gender identity is private until they have given permission for this to be shared.			
7. Listening well: I listen to the language individuals use to describe themselves and ask if I may use the same words.			
8. Respecting pronouns: I aim to use the name and gender pronoun 'she', 'he' or 'they' that people use about themselves (if in doubt, ask!).			
9. Keeping things open: if someone mentions a 'partner', I make no assumptions about their gender.			
10. Respecting closeness: I always check who the significant people are in a person's life and recognise they may not be biological family members.			
11. Offering private space: I give consideration to privacy for visiting LGBT friends and family.			
12. Listening to complaints: I treat people's concerns about language and attitudes seriously and understand that it can be hard for a person to make a complaint.			



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