
Dementia and the LGBT+ community: Roundtable notes

Seldom heard groups

People from seldom heard groups face barriers to accessing good health and social care, which at time fails to meet their needs. Challenges can include a lack of awareness and cultural understanding across health and social care settings. This problem has become more acute as public service budgets have been cut.

Through our diverse membership the DAA is well placed to improve this situation by harnessing the resources and ideas of our members and of other organisations operating across health and social care.

In June 2017 the DAA hosted a series of evidence gathering roundtables with leading stakeholders involved in delivering care and support of seldom heard groups. The roundtables covered dementia and learning disabilities, dementia within prison settings and within the LGBT+ community.

Introduction

People with dementia from the LGBT community are often marginalised and under-represented across health and social care settings; they can often be quite heteronormative, with many of their brochures and posters not presenting pictures of LGBT people in these. Research reveals that the current generation of older LGBT people also lack support from family members. They are more likely to live on their own, be single and childless – all of which may mean that they may find it harder to seek support or have people to depend on in order to receive adequate support

Roundtable

25 people came together on 21st June in London to discuss the key issues and actions to be taken around supporting people affected by dementia within LGBT+ communities. The DAA hosted this four-hour roundtable, with Sally Knocker chairing it. The attendees consisted of experts on LGBT+ and dementia, and carers and people with dementia from the LGBT+ community. The session saw us hearing the experiences from those affected by dementia, having small group discussions around the issues and what could be done about them, and agreeing on actions that this campaign could focus on for people to undertake.

Key themes

1. Training and awareness

Health and social care professionals need to be open and understanding of an individual's need. It's also important to consider that some cultural and religious different traditions are anti-LGBT. Demonstrations of commitment – such as rainbow logos, lanyards and banners – are important but they do not have the same impact unless all staff are committed to

understanding the needs of LGBT people and adopting an accepting attitude and approach. Language is very important and people should be trained on how to use LGBT-appropriate language

2. Family, friends and communities

It's important for LGBT people to be around other LGBT people, as they share similar experiences. So living in a rural community can sometimes bring about more challenges than living in somewhere such as London, for example. Many LGBT with dementia are more likely to be living alone, and do not have the support systems afforded to others.

3. Coming out and being open

LGBT people can find that typical, heterosexual support services are insufficient as they feel they cannot be as open about their lives, their experiences and who they are. People can often struggle with having to come out to health and social care professionals, as this can be an emotional and difficult thing to do repeatedly, especially when they are unsure of the response that they will receive - 'coming out' is an ongoing process.

4. Understand the person

Listen to the person who is standing in front of you, not the carer, family member etc. with them. Understanding the person's life stories is key, so health and care professionals can engage with them on a more personal level

5. Do not generalise or assume

There can be dangers of putting L, G, B and T together as an homogenous group as there are clearly distinct needs and sometimes individuals within these groups have not always mixed well, with bi and trans people sometime feeling particularly marginalised.

Recommendations

1. Training and awareness

- Incorporate training and awareness of LGBT groups in formal training for nursing, care home, care home commissioners and managers. Consult with Terrence Higgins Trust and Stonewall (and other established gay organisations)
- Identify where enhancement to equality training can be made to increase awareness of LGBT issues to people training to become care professionals (invite where possible speakers of people caring for a relative or friend to add real-life dimension to understanding)
- Incorporate LGBT issues into Dementia Training.

2. Trans

- DAA nationally needs to become better informed about the issues for trans people affected by dementia. This will involve further work to reach out to and identify people

who identify as trans and are, or have been, affected by dementia, who are able to describe their experiences and needs

- Further actions will need to be determined by what trans people affected by dementia say for themselves
- In the meantime however, training and awareness sessions need to recognise the existence of trans people affected by dementia, and appreciate that although there may be some overlap, most of the issues are very different for trans people than for those who are lesbian, gay or bisexual.

3. Conversations and stories

- Create a 'Dementia LGBT Story' resource, using videos of people sharing their lived experience. This would be useful as a tool for training and also a resource for LGBT people affected by dementia to go to
- Care providers are to ensure that they create biographies for their clients that are dynamic, and not continue to use an initial assessment biography as the source of their understanding of the client
- DAA members to commit to providing a story of LGBT lived experience in their service, assisting to demonstrate that there are many LGBT people out there, using lots of service and reinforcing why the call to action is needed.

4. Networks and partnerships

- Organisations to create links with local services for the LGBT community and investigate opportunities for shared working, but also to increase signposting options if a resident / client would benefit from a service. Bringing in external services for talks and advertising their services may contribute to the creation of LGBT friendly communities
- Dementia services/organisations and LGBT organisations need to be able to provide information about each other's services and need to ensure that contact details are kept up to date.

5. Demonstrating inclusivity

- Consider a 'Gold Standard' for LGBT care in care home and home support service providers. Need to develop agreed standards and objectives through consultation with accepted and knowledgeable partners/users. Possibly signed-off by and awarded by significant organisation/ Govt. Department or senior LGBT Organisation
- Organisations to update literature and images used to include the LGBT community, and acknowledge individuals who are LGBT already living in or using their services.
- Organisations to commit to a Policy check, similar to the Dementia Words Matter Call to Action. Do Policies create any barriers to the LGBT community, staff and service users for example use of terms such as husband, wife, partner and re-thinking what Next of Kin may mean, and acknowledging less 'traditional' terms or support networks for individuals
- Similarly, LGBT+ organisations should be encouraged to become "dementia-friendly" organisations, with awareness-raising and training followed by explicit commitments in information and promotional materials.

Acknowledgements

The DAA would like to thank the following people and organisations for participating in the roundtable and for their help and support of the campaign:

Lucy Whitman, Mike Parish, Patrick Ettenes, Rachel Dixey, Sandi Borgia, Sue Gallear, Tom Hughes.



OPENING DOORS
LONDON



The
ExtraCare
Charitable Trust

