DEMENTIA AND THE LGBT+ COMMUNITY

Background to the Dementia Action Alliance and this campaign

The Dementia Action Alliance (DAA) is a membership body and independent network of over 150 health and social care organisations in England to connect, share best practice and take action on dementia. They support its members to work in partnership, and inspire each other to adopt new practices that radically improve the health and social care outcomes of people affected by dementia. One such means is through its campaigns.

After surveying members to find out what they wished the DAA to campaign on, the deciding vote was post diagnostic support for people from seldom heard groups, which includes people from the LGBT community. The campaign has so far seen a briefing paper written on dementia in the LGBT community, a roundtable that produced a set of recommendations for people to implement to support people affected by dementia, meetings with LGBT organisations, and a launch event that saw people affected by dementia and professionals from the LGBT community discuss the extra support that is required for them.

The campaign is still running and its objectives are to raise awareness of the challenges faced by people with dementia from the LGBT community, influence system-wide change, and bring about organisational change by implementing the recommendations. The DAA are asking people to pledge to take action and share case studies, which will be made available on the DAA website.

Introduction

Do you have dementia or know of someone with it? What is the support like? This question generally tends to receive a mixed response. However have you thought about what it might be like to have dementia and be from the LGBT community? You might wonder why this would make any difference.

Anecdotally, we have heard that people with dementia from the LGBT community are often marginalised and under-represented across health and social care settings. For instance, according to Stonewall¹ one in eight LGBT people accessing social services in the last year have been discriminated against because of their sexual orientation and/or gender identity. Three in ten trans people have experienced this discrimination, and Black, Asian and minority ethnic LGBT people who have accessed social services within the last year are also more likely to have experienced discrimination (24%) as are LGBT disabled people (18%).

For reference, there are an estimated 850,000 people with dementia in the UK; and although it is not currently easy to calculate figures for the number of LGBT living in the country, surveys suggest that around 6% of the UK’s population currently define themselves as LGBT².

¹ www.stonewall.org.uk/sites/default/files/lgbt_in_britain_hate_crime.pdf
Under-representation and stigma

Stigma is unfortunately still present in relation to homosexuality, especially amongst people over 65. This means that should someone be asked about their sexuality, they may not state that they are LGBT and therefore will not receive appropriate and person-centred support (if they are lucky enough to receive care from an LGBT friendly provider).

Care settings

While the Equality Act guarantees protection from discrimination based on your sexuality or gender, prejudice and stigma is still widespread in care settings, which results in many places not providing appropriate, sensitive and person-centred support to LGBT people with dementia. As a consequence, in many cases their needs are not met.

Heteronormativity

Many care settings deliver heteronormative care and support, not taking into consideration that their residents, patients or service users with dementia may not identify as heterosexual. This can be seen in marketing materials showing opposite sex couples, and assuming the use of terms such as ‘husband’ or ‘he’ instead of ‘partner’ or ‘they’. Both of these can be easily rectified through training and awareness raising and by presenting same sex couples in materials and to not automatically assume that everyone is firstly, in a relationship, and also, heterosexual.

Activities

Many care settings engage in activities using people’s memories, backgrounds and stories. If sexuality has not been discussed or the staff is not LGBT friendly, this can make activities more difficult as the person living with dementia may feel the need to omit the most important parts of their life, or may receive negative responses from staff and other residents if they are open.

The support of families

Families may be unsupportive of a person’s sexuality or gender change and therefore may not disclose their identity to staff, or worse still, request that staff do not encourage or allow any behaviour that is not deemed to be heterosexual and/or cisgender. As a consequence, LGBT people with dementia may become distressed, while the care setting will be unable to support their individual needs sufficiently, as this could result in complaints from the family.

Staff

Even if a care setting is inclusive and providing good quality care, a pervading issue within the sector is certain staff members’ views of homosexual and trans people. Some care setting staff members are unaccepting of LGBT people, due to religious or cultural views of

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3 Morrow, Deana “Older Gays and Lesbians: Surviving a generation of hate and violence”, 2001
4 Heteronormativity: a view that promotes heterosexuality as the normal/preferred sexual orientation
5 “Cisgender – someone whose gender identity is the same as the sex they were assigned at birth” www.stonewall.org.uk/help-advice/glossary-terms
homosexuality in their home countries. As a result, there have been many recorded instances of staff members discriminating against LGBT residents with dementia.

**Partners**

For residents of care homes with or without a partner, policies and training should be in place to allow same-sex relationships to be engaged in, including being intimate. For patients in hospital, partners should have the same visitation rights as heterosexual couples and should be consulted with about the care their partner with dementia receives. When day centres carry out assessments of the service user prior to them attending, they should ensure that the partner is as involved as possible and can provide plenty of information to the day centre about them.

**Transgender residents**

Transgender people are faced with a different set of challenges to LGB people when they develop dementia, which requires specific support. One of the most common issues that has been raised is that transgender people may revert back to their birth gender as their dementia progresses. As a result, they can feel anxious, confused and upset due to their dysphoria.

**Conclusion**

This overview is brief and by no means exhaustive. Although we have seen an increase in the awareness of LGBT people with dementia, there is still a lot more that needs to be done.

- People should not feel that they cannot speak openly about their life and relationships and a way to make people feel more comfortable is for people and care settings to be more inclusive.
- Staff need to be aware that the family of someone from the LGBT community may not necessarily be their blood family, yet they should still have the same legal rights and amount of input into that person’s care; as should the partner. It is vital that they are fully accepted by staff and involved in all communication and support.
- Residents should feel able to be involved in same-sex relationships within the care setting without there being the risk of discrimination, and staff should allow the partner of the resident to be affectionate and/ or intimate without any judgement.
- There are further complexities for transgender people, including cross-dressing, reverting to their previous gender, medical implications and stigma.

One of the articles of the Human Rights Act is the prohibition of discrimination and therefore we must support people with dementia in the LGBT community with actions that focus on awareness raising, training, and most importantly, personalised care.

**Further information**

- [From Seldom Heard to Seen and Heard campaign](#)
- [DAA website](#)
- [Twitter](#)
- [Email](#)