

Dementia and the Lesbian, Gay, Bisexual and Transgender (LGBT+) Community

Roundtable discussion briefing paper



National Dementia Action Alliance

INTRODUCTION TO CAMPAIGN

This briefing paper has been produced to launch the National Dementia Action Alliance's (NDAA) campaign to improve care and support for people affected by dementia from seldom heard groups.

ABOUT THE NDAA

The NDAA is a network of organisations who commit to taking action on dementia. Through our work, we aim to improve health and social outcomes for people affected by dementia. The NDAA was set up in 2011 following the government's National Dementia Strategy of England, to bring together key organisations to gain their commitments to achieving the outcomes outlined in the strategy. Since then it has gone from strength to strength and we now have over 150 members.

The role of the NDAA is to bring together our members to connect, share best practice and take action on dementia. We also campaign on key issues affecting people with dementia and their carers. Past campaigns we have organised have improved dementia care within hospital settings, reduced anti-psychotic drug prescriptions and improved support for carers.

Our 2017 campaign will focus on improving care and support for people affected by dementia who come from seldom heard groups. The campaign has three primary objectives:

1. Raise awareness of the challenges faced by people with dementia from seldom heard groups
2. Influence system wide change
3. Bring about organisational change

As part of the campaign we will hold a series of roundtables, each focusing on a specific seldom heard group. Through the roundtables we will explore areas where progress is needed and where the NDAA, through the influence of its members, can affect wider change.

We will run roundtables focused on dementia in the following groups:

- Prisons
- Lesbian Gay Bisexual & Transgender (LGBT+)
- Learning disabilities

DEMENTIA AND THE LGBT+ COMMUNITY

Overview of main issues

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 LGBT¹.

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 Stonewall² one in eight LGBT people (12 per cent) 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 (29 per cent) 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 per cent) as are LGBT disabled people (18 per cent).

Studies, such as Stonewall's report, clearly indicate that LGBT people face a number of barriers when accessing services and are often stigmatised. In general, discussion around sexuality amongst older people remains a taboo and this only increases in relation to the LGBT community. If an LGBT person then develops dementia, they are even more likely to face stigma, due to health and social care professionals' lack of awareness and understanding around the condition.

A large proportion of LGBT people who are currently over 65 will have lost their family connections and/or may have not had their relationships formally recognised. During the majority of the 20th Century (and still in many countries today), LGBT identifying people were and continue to be shunned, pitied or marginalised. While in many ways, the UK has progressed in terms of its perceptions of homosexuality, there are remaining legacies that translate into poor care for LGBT people with dementia in care homes. For instance, we have heard that there is lack of acknowledgement of LGBT peoples' relationships in the care that they receive in care settings, and a suppression of their ability to express their sexuality and/or gender.

Research reveals that the current generation of older LGBT people also lack support from family members³. 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 support⁴. This in turn increases the likelihood of social isolation

¹ Chalabi, Mona, www.theguardian.com/politics/reality-check/2013/oct/03/gay-britain-what-do-statistics-say, October 2013. The number of people identifying as LGBT will likely increase in the future: www.bbc.co.uk/news/uk-37560539

² http://www.stonewall.org.uk/sites/default/files/lgbt_in_britain_hate_crime.pdf

³ Stonewall report

⁴ Alzheimer's Society factsheet

and loneliness amongst older LGBT people who also have dementia, which in itself increases the risk of these feelings.

Under-representation and stigma

It can be a challenge to identify people affected by dementia who are from the LGBT community. This can be for a number of reasons. Firstly, people generally do not get asked their sexuality when they receive a diagnosis, enter a care home, or get admitted to hospital. Another important consideration is that stigma is unfortunately still present in relation to homosexuality, especially amongst people over 65⁵. 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).

One of the major issues we face is that it is difficult to even find out what LGBT peoples' experiences of care are, as they are under-represented in surveys. When carrying out studies, researchers have found it difficult to engage with LGBT people with dementia, likely due to their fear of coming forward and the heightened stigma they face. However, it is key that we find out about their unique experiences, as developing robust research is essential in ensuring that care can be personalised and improved. Living with dementia can result in a person displaying behaviour that is out of the ordinary for them. Adding to this, if people who have been closeted their entire life – due to persecution, stigma, or abuse - begin to display affection towards the same sex, an assumption could be made that this is just part of their dementia.

Care settings

A care setting can be described as anywhere where an individual receives health care. Being admitted in to hospital, a care home or receiving homecare with dementia can be a frightening experience for anyone, and may be even more daunting for LGBT people with dementia.

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.

⁵ Morrow, Deana "Older Gays and Lesbians: Surviving a generation of hate and violence", 2001

Heteronormativity⁶

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 perceived as a form of discrimination towards residents who identify as LGBT and should be taken into consideration as one would do with religion or disability. 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. By using open and inclusive language, the person with dementia feels more comfortable to come out about their sexuality, should they wish to. People should not be forced to disclose their sexuality if they do not wish to do so. However, we need to ensure that there is an overview of what is in place for LGBT identifying people with dementia in care settings to ensure that they are inclusive.

Activities

Many care settings engage in activities using people's memories, backgrounds and stories. For example, they may speak to residents or service users about their childhood, family and work. 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. Care homes often have support groups (the majority of which are not LGBT specific), which LGBT people may feel uncomfortable attending due to references to their family. Someone who identifies as LGBT may feel uncomfortable or fearful when discussing their personal life, which may include a same sex partner and/or an unsupportive family.

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 cisgender⁷. 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.

⁶ Heteronormativity can be defined as: a world view that promotes heterosexuality as the normal or preferred sexual orientation.

⁷ "Cisgender or Cis – someone whose gender identity is the same as the sex they were assigned at birth. Non-trans is also used by some people" www.stonewall.org.uk/help-advice/glossary-terms

For LGBT people over 65 with dementia, their family may consist of close friends rather than traditional family relations and often care settings do not take this into consideration. We believe that the care setting should involve and communicate with the chosen family in regards to provision of care (with the consent of the person affected), as partners should be involved in every aspect of communication and care.

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 homosexuality in their home countries. As a result, there have been many recorded instances of staff members discriminating against LGBT residents with dementia.

This is why many LGBT people with dementia often do not disclose their sexuality to care staff, which leads them to hiding their sexuality or gender upon entering a care setting. Care staff may give someone from the LGBT community generic support, either due to homophobic views, a lack of awareness of dementia or both (which has a deepened effect on the care that LGBT people with dementia receive).

To make matters worse, other residents, patients or service users may also react and engage negatively if they know that someone identifies as LGBT, which is in large part due to heightened stigma amongst older generations. Staff need to ensure that they treat each resident on an individual basis, taking into consideration their identity, background, needs and beliefs, whilst not assuming that all people within a care setting are straight, cisgender, married and with children.

In order to overcome the major issue of homophobia within care settings, staff should be given training on the needs of the LGBT community and specific guidance on the specific issues relating to dementia. In addition, in order to create an LGBT friendly environment, care settings should nominate a Diversity/Equality Champion, to ensure that that a care setting is inclusive. Diversity/equality teams or staff members are important to help ensure that all staff members act in an inclusive way, deliver training, and are aware of the appropriate policies.

Partners

An example of good practice amongst staff could be allowing a care home resident's same-sex partner to bathe them, or show affection in front of others without the risk of upsetting others. 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. This does, however, need to be treated sensitively and as a case-by-case scenario.

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. As the partner will not be as present at a day centre as in a hospital or care home, then staff may not be aware of their relationship.

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. For trans people with dementia who have reverted back to the gender that they were born with, several specific issues may arise in care settings. Namely, should a male or female clean them and how should they be dressed?

Additionally, trans people with dementia may be living with medical issues relating to the gender that they were born with that begin to emerge when the person ages. For instance, a trans woman with dementia may get a diagnosis of prostate cancer. It is therefore extremely important that their health is cared for properly. For a trans resident with dementia it may be difficult to remember to take their hormone treatment or other vital drugs and this can have a negative impact on the mental health of the person if this is not rigorously controlled.

Trans people may cross-dress as a result of their dementia, because of confusion relating to their gender expression, or because they have repressed the urge their entire life and now feel liberated to do so. Regardless of the reason, a care setting should have plans in place for when this happens. They should not be stopped, reprimanded or judged. It is the person's decision to do so and they should be made to feel as comfortable as possible.

Conclusion

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.