Dementia care and LGBT communities:
A good practice paper
April 2016
Introduction

Dementia and lesbian, gay, bisexual and transgender (LGBT) people

The UK is home to an estimated 1.2 million older lesbian and gay people in the UK, yet they are an invisible population and rarely acknowledged by service providers and commissioners.

This issue was summarised by the Social Care Institute for Excellence briefing, Working with lesbian, gay, bisexual and transgender people, which describes how “commissioners and providers don’t often think about LGBT people when planning and delivering services, but this does not mean that LGBT people are not using services or do not want to use services.”

While the existence of a National Dementia Strategy has helped to ensure that dementia is at the top of the national agenda and the Alzheimer’s Society estimates that there will be an estimated 1 million people with dementia in the UK by 2025, there is no specific reference to LGBT issues in the strategy.

About this report

Such concerns provide the backdrop to this short case study-based report, which is the second piece of work from our partnership that explores specific support for LGBT people with dementia. This report is published by the National Care Forum (NCF) and the Voluntary Organisations Disability Group (VODG), working with the National LGB&T Partnership, as part of the Department of Health’s Strategic Partnership Programme.

Our work focuses on the needs of the LGBT communities, exploring how care professionals can provide more appropriate support. This report can be seen to complement our other recent publication, Dementia: equity and rights, which includes themes for individuals, carers, commissioners and service providers in relation to equity issues in dementia.

The background to this report

Our report has been developed from an initial piece of work in 2014-15 - a roundtable event and a subsequent paper, The dementia challenge for LGBT communities. The publication you read here is a response to concerns, raised at the roundtable and reflected in the related paper, that more awareness is needed about good practice in supporting an under-served group of people.

While LGBT people with dementia share some of the same experiences as heterosexual people living with dementia, there will be many issues that are not the same. As other research has underlined, LGBT people with dementia have specific health needs along with the usual care and support issues as everyone else as they age.

5 Dementia: equity and rights, April 2016, available to download from National Care Forum http://www.nationalcareforum.org.uk/ or VODG (http://www.vodg.org.uk/)
For example, the challenges highlighted in our initial piece of work include:

- People worrying about being forced “back into the closet” in later life because of the attitudes of care staff
- LGBT older people being more likely to be estranged from relatives and lacking family support, which makes formal care even more important than it is for their heterosexual peers
- Some people losing their inhibitions due to dementia, while others who have previously come out feel unable to be open about their sexuality or transgender status
- The anguish and confusion caused by dementia being exacerbated as LGBT people with the condition struggle to deal with negative perceptions of their sexuality or gender in residential care.

A rights-based approach to supporting LGBT people with dementia

LGBT people with dementia have specific support needs, as our earlier work reflects. While most care and support professionals strive to give equitable treatment to the people they support. But this approach, although well intentioned, risks ignoring the very differing needs of LGBT people with dementia.

Our work supports a rights-based approach to dementia; it is our view that dementia be regarded as a disability. As stated in a recent paper from the Mental Health Foundation, *Dementia, rights, and the social model of disability*, dementia can be seen within the Equality Act’s legal framework as a disability. People from LGBT communities, for example, may have other protected characteristics (the grounds on which discrimination is unlawful under the *Equality Act 2010*).

The case studies

While this short report is by no means a comprehensive look at the way forward for the support of LGBT people with dementia, it offers a glimpse into the possibilities for good practice. Our three examples show:

- how to involve LGBT people in shaping policies and practices on dementia care
- the importance of a partnership approach between health, social care and voluntary sector when supporting LGBT people with dementia
- the vital role of research in developing and refining methods of support; this can involve, for example, LGBT people’s hopes for their future care

Purpose of this report

As the Mental Health Foundation paper on dementia and rights states: “There isn’t much that we can do about dementia at the moment. But, there is a lot we can do about the environment and the experiences that people have.”

We hope that the approach described on the following pages goes a little way in helping to achieve this aim.
When Rowena McCarthy first moved back to London from her Derbyshire village into an Anchor sheltered housing scheme in London, a fear of prejudice led her to hide her sexuality from fellow residents.

For a year, she led two separate lives: one in the housing scheme with a false, heterosexual identity, and one outside the scheme, where she was able to enjoy her own interests and go to LGBT events. If neighbours asked what she was doing – she would tell them she was “just going out”.

Eight years on, and housing association Anchor has supported Rowena, now 72, to come out to her fellow residents. She chairs the organisation’s nationally acclaimed LGBT advisory group. The group aims to make Anchor a safe and welcoming environment, both for LGBT people living in organisation’s housing and for those employed by it. It promotes Anchor as a LGBT-friendly organisation, provides support and guidance to other residents and staff and acts as a sounding board for Anchor on LGBT issues.

Experiences like Rowena’s and the work of the group have influenced the housing association’s focus on the issue of dementia in LGBT communities.

Brenda Metcalfe, Anchor’s customer engagement manager who launched the group in 2007, says: “Generally speaking, older LGBT people tend to be more isolated because they’re less likely to have children than their heterosexual counterparts; they may be estranged from their family and feel more isolated. This isolation is compounded if you also have dementia. For example, people with dementia who are moving into a care home rely even more on family to help them prepare for the move, to come in and support them and ensure staff get to know them; someone from the LGBT community may not have that same network.”

Anchor is working on a new project to investigate the challenges facing LGBT people in its care homes and, Brenda says, “by its very nature, the research will involve dementia and LGBT issues”. She explains: “We want to identify where we can make further improvements for LGBT people: how we market our homes; what training we give to staff; how easy is it for older people to have private time with their partners.”

Supported by researchers from Middlesex University, the scheme will involve a team of twelve peer reviewers – volunteers from the LGBT community recruited from among its residents, staff and family members – who will visit Anchor homes to effectively audit the level of care and support for older LGBT people.

The project’s existence reflects the influence of the landlord’s advisory group, which is open to all gay, lesbian, bisexual or trans colleagues and residents. Set up as a direct result of listening to residents like Rowena, its purposes include benchmarking activities with other organisations, sharing best practice, and educating residents and staff on living and working with diverse groups. The group is funded through Anchor’s customer service engagement budget and approximately £6,000 a year, mostly on meeting room hire, travel and overnight accommodation for members travelling nationally to meetings.

11 Anchor http://www.anchor.org.uk/
The group, which meets thrice a year in different LGBT-friendly community venues around the country, regularly hears from a range of guest speakers (recent sessions include those from a local authority LGBT housing worker and a police officer specialising in hate crime). Group members also speak at internal employee conferences or at other events within the housing and care sector. Up to 24 people attend the meetings regularly (the national membership is much larger and the group are developing an online forum which means those who are unable to attend in person can still participate.)

Members of the LBGT group work closely with a number of other housing organisations including Stonewall Housing, Tenant Participation Advisory Service and the Chartered Institute of Housing, to help share best practice.

One of the main areas of work is advising Anchor on policies or helping to write staff guidance notes. So along with shaping housing management service standards and service delivery, members discuss how to ensure equality and diversity in Anchor services and in its standards for staff. With such aims in mind, the group helped draft staff guidance which includes a glossary of acceptable LGBT terms. Among other things, the practical handbook sets out what language may be appropriate when supporting LGBT people and how staff can spot and challenge prejudice towards LGBT residents, if it arises.

Organisations seeking to launch similar advisory groups, as Brenda says, must be aware of the challenges to overcome. Brenda also says board-level support is vital, as is the need to create an environment where people can talk openly and in confidence.

“As an organisation, it’s about being open and proud of what you do in this area – we’ve had stalls at lots of Pride events, for example, we try to share what we do, because we are proud of the group’s work. It’s also about the imagery you use, in your brochures, and the language used etc.

“We’ve had homophobic reactions, some tenants don’t believe we should running something like this someone threatened to withhold their rent, for example. But we’re very clear – so we explain that we respect everyone’s opinion, but if they feel they don’t want to pay us rent, then maybe Anchor’s not right place for them.”

Key learning points from Anchor’s LGBT advisory group:

• a clear purpose is vital; Anchor’s group promotes the housing association as a LGBT-friendly organisation, supports other residents and staff and is a sounding board for Anchor on LGBT issues

• members advise Anchor on policies or help to write staff guidance notes, shaping service delivery and ensuring equality and diversity

• meeting in different LGBT-friendly community venues around the country, enables more people to attend

• guest speakers add value, a police officer specialising in hate crime, for example

• group members can spread word by speaking at internal employee conferences or at other events within the housing and care sector

• board-level support for such groups is vital, as is creating an environment where people can talk openly.
Sue* had been living at her care home in rural Durham for a while when staff noticed how confused and agitated she was becoming about her gender identity.

Diagnosed with a variant of Alzheimer’s just before her 60th birthday, Sue had initially managed to continue living alone, but had to move into residential care when her symptoms progressed and it was clear she needed round-the-clock care.

At the care home, staff grew more worried as Sue began to refer to herself as “Cliff”. During these increasingly frequent episodes, they were unsure how to support her. She would become distressed by her appearance and unsettled by her physicality. These episodes became more frequent and the care home was at a loss as to how to support her.

Because care managers had no contact with Sue’s family and no idea of her medical history, they were unaware that she was a trans woman. Sue had been estranged from her family since they had rejected her following her decision to transition in the late 1970s. She had completed gender reassignment surgery at the age of 42.

A social worker at the care home sought the support and advice of local community-led charity Gay Advice Darlington/Durham\(^2\) (GADD) on how to work with Sue and remain sensitive to her gender identity. GADD, set up in 2002 to support LGBT people, formed a partnership group between the local authority social services and Sue’s GP – who was the only one who knew her medical history.

United in their aim to support the particular needs of a trans service user with dementia, the partners’ approach enabled all agencies to share knowledge and skills to collaborate on a new care plan. Using memory books and encouraging a personal sense of gender, the plan reinforced Sue’s identity. In addition, care home staff received awareness training on trans identities, including the impact of stigma and misgendering - being labelled by someone as having a gender other than the one you identify with - especially during the episodes of regression.

As Sue’s dementia became more severe, staff were able to offer her appropriate care and support, confident in the knowledge that their approach was tailored to her very personal needs and gender history. Not only did this approach benefit Sue’s wellbeing and quality of life, but all the partners involved in her care plan gained a stronger understanding of the issues faced by trans service users and delivered more empathic care.

Through their experience with Sue, health, care and social services staff developed their knowledge and skills around LGBT people’s needs, and are using this to improve their and care provision for other people they support in the future.

\(^2\) Gay Advice Darlington/Durham http://gayadvicedarlington.co.uk/
Key learning points from Gay Advice Darlington/Durham:

• a partnership approach in supporting trans service users with dementia can involve care staff, local authority social services, GPs and specialist voluntary sector agencies, all collaborating on a care plan

• partners should outline, clarify and agree the aim - improving the wellbeing and quality of life of the person being supported - and be specific about each agency’s area of expertise, knowledge and skills

• it is important to have an awareness that care and support plans may need to be regularly revised and amended as someone’s dementia progresses

• while each person supported will require a unique approach, staff at each agency can use the experience and knowledge gained from individual care plans to develop and strengthen future work with other LGBT people with dementia.

*Sue is a pseudonym*
Over the rainbow

When Clive*, in his 70s, came out to the carers supporting his partner who had dementia, the carers replied that they treated everybody the same. While the response sought to reassure Clive, it also led him to question how far service providers truly consider the specific support needs and sexual identities of LGBT people. Clive said: “We immediately said ‘that’s not what we want’. We don’t want to be treated the same…we want to be treated as a gay couple.”

Clive, who lives in London, shared his concerns as part of a research project exploring the issue of dementia support for LGBT people.

The research, *Over the Rainbow, Lesbian, Gay Bisexual and Trans People and Dementia project*[^13], was led by the University of Worcester Association for Dementia Studies and funded by the Dementia Engagement and Empowerment Project (DEEP). DEEP supports a network of people with dementia who want to influence policy and practice and is led by the Innovations in Dementia in partnership with the Mental Health Foundation, and funded by the Joseph Rowntree Foundation and Comic Relief.

The University of Worcester project’s final report, published in February 2015, reflects how LGBT issues might be mainstreamed in dementia care. It sets out practical actions for health and social care professionals that could improve the quality of support, particularly in residential care.

Research workshops were held in Birmingham and London. Participants included LGBT people who care for family members or partners with dementia. The fact that the Over the Rainbow project was unable to engage any LGBT people with dementia to get involved in the research reflects the challenge involved in reaching this largely invisible group of people.

The work was led by Elizabeth Peel, then Professor of Psychology and Social Change at the University of Worcester's Institute of Health and Society and now Professor of Communication and Social Interaction at Loughborough University. The overarching issue, says Professor Peel of the recommendations in the report, is that of staff training: “Education and training in awareness of gender and sexuality issues can vastly improve the experience of LGBT people with dementia.”

Training and awareness might involve language and communication issues, as the Over the Rainbow research underlines. According to one participant in the study, a care home should “come out” first, if it genuinely seeks to support LGBT people.

The fact that the care setting is a non-discriminatory environment can be signaled by something as simple as photographs of same-sex couples in marketing literature, or ensuring that staff use gender neutral pronouns, which can encourage someone to come out.

Professor Peel suggests that there may be value in some kind of kite-mark as a reassuring sign that fosters a sense of safety and confidence. She adds: “This could be one possible indicator that might be helpful, as long as it is backed up by actual commitment and training.”

Another area of action is ensuring reminiscence activities are delivered in a more supportive way: “You have to take a culturally sensitive approach…there’s an added challenge around trans issues - so if you’re reminiscing with a trans person later in life, you may be taking them to their childhood where their gender is different. We have this notion of reminiscence always being positive, but it depends on the experience that you’re taking someone back to.”

Recognising that LGBT people might have a wide support network involving those who are not family members is important, as is appreciating the fact they may be in a legal relationship like a civil partnership. Professor Peel adds: “Some LGBT people might not have a recognised partner, but may have a network of friends that they treat like kin, but are not necessarily socially recognised as such; staff need to appreciate that not everyone has what might be regarded as a conventional model of ‘family’.

On the issue of supportive networks, LGBT people with dementia and their carers might benefit from innovative models of support. Social media, for example, might be useful. For Clive, for example, “one of the great things about the twitter community is that there is more and more people with dementia that are using it…it’s just a matter of feeling you’re not alone”.

Professor Peel adds: “The traditional model is a dementia café – a physical space in the community - but if you have geographically dispersed groups, online communication will help. Support staff could develop some kind of virtual interventions that might support LGBT people to engage with each other.”

Ultimately, Professor Peel’s research emphasises, while the person-centred approach is well established in social care and in dementia research, policy and practice, it is notably absent in the context of LGBT people with the condition. The Over the Rainbow report suggests that “the multiple identities that intersect with age, gender, disability, social class, ethnicity and individual biographies and experiences” are underestimated; LGBT people with dementia must be seen as a “people first” and foremost.

Professor Peel concludes: “This very invisible population will grow over time and we need to address their needs; these are important social justice and diversity issues and reflect how we value people and their identities.”
Key learning points from Over the rainbow:

- education and training of staff caring for LGBT people with dementia is fundamental; this might involve encouraging the use of gender neutral pronouns
- care settings should show that they are non-discriminatory environments; showing same-sex couples in marketing materials is one way to achieve this
- reminiscence activities should be delivered sensitively, with awareness that people may be returned to a challenging time in terms of their sexuality or gender identity
- it is important to recognise that LGBT people might have a wide support network involving those who are not conventional family members
- innovative models of support networks for family carers, for example, might involve the use of social media
- using a person-centred approach, well established in social care should encourage staff to regard LGBT people with dementia as “people first”.


* Clive is a pseudonym
Conclusion

Earlier in this report, we described the challenge that exists in the care of older LGBT people with dementia. We also described some innovative methods of support by organisations delivering good practice to these under-served communities.

The three examples in this report are underpinned by a person-centred, rights-based approach (see the Over the Rainbow case study on page 11), something that our partnership identified as crucial in a previous piece of work14.

Key learning points

In addition, the examples reflect several key learning points that other care providers may use to influence and shape their support services.

These include:

• establishing a clear purpose that an organisation is LGBT-friendly, and ensuring that this aim is supported at board-level

• educating the workforce; developing specialist LGBT training materials for staff, such as guidelines encouraging the use of gender neutral pronouns

• promoting diversity, inclusion and presenting the environment as non-discriminatory; with same-sex couples in marketing materials, for example

• designing support sessions such as reminiscence activities sensitively and appropriately, to avoid returning people to a challenging period in their sexuality or gender identity

• recognising the value of peer-led networks and lived experience – both as a support for individuals supported and as a sounding board to advise on policy

• an awareness that LGBT people might have a wide support network involving those who are not conventional family members

• ensuring that partnership approaches to support – for example, those involving care staff, social services, healthcare professionals and voluntary sector agencies – enable all partners to collaborate on care and support plans.

Furthermore, something that is beyond the remit of this report but is described in other work we have published, *Dementia: equity and rights*[^15], is the need for action among commissioners. Health and Wellbeing Boards and local authorities, for example, should work closely with clinical commissioning groups to promote the integration of health and social care that recognises the specific needs of LGBT people.

### Future research

Equally vital, as we mentioned earlier in this report, is the need for more research into the support needs of older LGBT people with dementia. In its recent literature review, *Prevalence of dementia in population groups by protected characteristics*[^16], Public Health England states: “Dementia research should be a career opportunity of choice, and the UK the best place for dementia research via a partnership between patients, researchers, funders and society. Funding for dementia research should double by 2025…This would lead to world-class facilities and infrastructure, drive capacity building, and speed up discovery and implementation.”

Our partnership firmly believes that local and national research needs to take account of the wider variety of characteristics that can affect people’s experience of dementia. Dementia-related studies should consider building in equity from the start, and consideration should be given to commissioning dedicated studies to develop our understanding of particular characteristics.

### This partnership’s next steps

Building on our already published work, we plan to co-produce an awareness raising resource for adult social care providers. This will aim to support staff working with LGBT people with dementia. The work may include a quality mark to inform potential users of their services of their commitment to providing appropriate support. Such work will develop the approach we touch upon in this report - that dementia in itself is a disability and necessitates a rights-based approach to support.

This transformation in mindset is vital if older LGBT people with dementia are not to be furthered disadvantaged by the very people responsible for their support.


A glossary of terms: sex, sexual orientation and gender identity

**Biological sex** refers to outward sexual appearance. For example, having the reproductive organs of a male or a female. The human brain also has male and female characteristics.

**Biphobia** The irrational fear, hatred, and discriminatory treatment of people who are bisexual.

**Bisexual** men and women have a sexual orientation involving physical or romantic attraction towards both men and women.

‘Coming out’ refers to a lesbian, gay, bisexual person disclosing their sexual orientation; or a transgender person disclosing their gender identity.

**Discrimination** making a positive or negative judgement about someone based on bias, assumptions or prejudice. Discrimination can either be direct or indirect.

**Diversity** an appreciation that each individual is unique giving recognition to individual differences. For example, age, race, ethnicity, gender, sexual orientation, disability, religion or belief.

**Equal opportunity** not excluding individuals from the activities of the society in which they live: for example, employment, education and health care.

**Gay, gay man or homosexual** are used to refer to a man who has a sexual orientation towards another man.

**Gender identity** refers to the inner sense of knowing that a person is a man or a woman.

**Gender reassignment** the process of identifying and living in a new gender, with or without hormone therapy, also called transition. Gender reassignment refers to the process of transitioning from the gender assigned at birth to the gender the person identifies with. Some transsexuals may decide to change their bodies through hormone therapy or gender reassignment, but not all will.

**Gender role** refers to those cultural, and behavioural characteristics typically associated with being a man or a woman in society.

**Heterosexism** discrimination directed against non-heterosexual behaviour. This can be because of cultural or social prejudice against LGB people. It is based on an assumption that heterosexuality is superior to any other form of sexual orientation.

**Homophobia** irrational fear of, or prejudice and discrimination against gay men, bisexuals and lesbians.

**Intersex** describes people who are born with reproductive organs, genitalia and or sex chromosomes that are not exclusively male or female.

**Lesbian, gay woman or homosexual** are used to refer to a woman who has a sexual orientation towards another woman. Great sensitivity should be exercised when using the word homosexual; the term is rooted in a 19th century assertion of same sex attraction being a mental illness or medical problem, so some people may find it unacceptable.

**Transgender** an umbrella term used to describe people whose gender identity or expression differs from their birth sex. Transgender is not a sexual orientation. However, transgender people may identify as lesbian, gay, bisexual or heterosexual. The term transgender may sometimes include the term transsexual which refers to a person who wants to or who has already changed their physical sex from the one which they were born with.

**LGBT** lesbian, gay, bisexual and transgender people.

**Prejudice** a view about someone is based on a lack of knowledge, a pre-conceived idea or on social pressure.
Queer originally a derogatory term used to verbally abuse LGBT people. Now, however, the word queer is sometimes used by some LGBT people and groups to identify themselves.

Sexuality refers to how men and women express themselves as sexual beings.

Sexual orientation is a combination of emotional, romantic, sexual or affectionate attraction to another person. It is not the same as sex or gender.

Trans a generic term generally used by those who identify themselves as transgender or transsexual. Many transgender people can identify as female-to-male (FtM) or male-to-female (MtF).

Transphobia irrational fear, hatred, and discriminatory treatment of people who are Transsexual a person who wants to or who has already changed their physical sex from the one which they were born with. Not all transgender people are transsexual.

The law and LGBT people

As well as the general freedom of expression legislation in the Human Rights Act 1998, there are a number of specific laws relating to sexual orientation and gender identity:

Sex Discrimination (Gender Reassignment) Regulations 1999: aim to prevent discrimination against transsexual people on the grounds of sex in employment and vocational training.

Employment Equality (Sexual Orientation) Regulations 2003: makes it unlawful to discriminate on the grounds of sexual orientation.

Civil Partnership Act 2004: gives same-sex couples the right to register a civil partnership, which meant that the partnership was legally recognised.

Marriage (Same Sex Couples) Act 2013: gives same sex couples the right to marry in civil ceremonies.

Gender Recognition Act 2004: gives transsexual people the right to apply for a Gender Recognition Certificate.

The Equality Act 2010: replacing and updating the Equality Act 2006, this aims to consolidate existing anti-discrimination legislation, including that relating to gender reassignment and sexual orientation.

Public sector equality duties 2011 require organisations to give ‘due regard’ to the need to eliminate discrimination, advance equality of opportunity and foster good relationships.

Glossary based on the Chartered Institute of Housing practice brief Delivering housing services to lesbian, gay, bisexual and transgender customers

17 CIH Delivering housing services to lesbian, gay, bisexual and transgender customers http://www.cih.org/resources/PDF/Regional%20Support/NW%20resources/John%20Thornhill.pdf

A good practice paper