

THE DEMENTIA CHALLENGE FOR LGBT COMMUNITIES:



**a paper based
on a roundtable
discussion,
2 December 2014**

LGBT dementia roundtable participants:

Jane Ashcroft - Anchor Housing, chief executive,
Jenny-Anne Bishop - TransForum Manchester, group co-ordinator
Gill Boston - National Care Forum, programme manager
Dennis Carney - Public Health England, project support officer
Sue Davis - LGBT campaigner
Paula Dooley - GIRES (Gender Identity Research and Education Society)
Nick Dykes - CLS/Belong, chief executive
Des Kelly - National Care Forum, executive director
Nardia Lloyd-Ashton - Skills for Care, locality manager
Margaret Madden - Salford City West housing association, head of independent living
Carol Mitchell - Skills for Care, locality manager
Sian Payne - LGB&T Partnership/Lesbian and Gay Foundation, director of organisational development
Becca Spavin - Department of Health, dementia team

Apologies from the following who were unable to attend due to previous commitments:

Ellie Burns - Department of Health, adult social care informatics lead
Bob Green - Stonewall Housing, chief executive, for National LGB&T Partnership
Paul Roberts - LGBT Consortium, chief executive, for National LGB&T Partnership
Sue Westwood - School of Health Sciences University of Surrey, lecturer
Professor Stephen Whittle - Manchester Metropolitan University



Sue Ryder

THE DEMENTIA CHALLENGE

"I am dependent on carers and I am frightened... what if they find out that I am a lesbian... what are they going to do to me... I have de-gay'd my house... this is much worse than the 50s. I want to be able to be gay in my last days – I don't want to have to hide again and I particularly don't want to have to hide because the home help is coming round..."

These words from an older woman* reflect the challenges facing lesbian, gay, bisexual and transgender people (LGBT) who need support as they age.

Dementia is at the top of the national agenda, as reflected in the National Dementia Strategy¹; by 2025, according to the Alzheimer's Society, there will be an estimated 1 million people with dementia in the UK. However, there is no specific reference to LGBT issues in the National Dementia Strategy, despite the fact that LGBT communities may also have other protected characteristics (the grounds on which discrimination is unlawful²) that demand distinct social care support.

■ The aim of the roundtable debate

Such concerns were the focus of a recent roundtable held by the National LGBT Partnership³ with the National Care Forum⁴, Sue Ryder⁵ and the Voluntary Organisations Disability Group⁶ – the organisations collaborate under the Department of Health Strategic Partner Programme⁷. The aim was to consider the needs of LGBT people with dementia and how the social care workforce could provide more appropriate support.

■ Policy – and prejudice

Participants began by acknowledging that dementia will remain a national priority regardless of the outcome of May's general election. One speaker said: "It doesn't matter what make up the government has, dementia is something anyone will want to focus on and improve outcomes for." It is therefore both timely and vital, the group noted, that approaches to the support get more attention.

In a reflection of the scant research into the subject, it is hard to state a figure for the LGBT population. However, some estimates put the older lesbian and gay community in the UK at 1.2 million⁸.

There is a risk, the roundtable heard, that social care professionals underestimate the needs of LGBT people. Studies⁹ have shown that while people face the same health and care issues as everyone else as they age, they have specific health needs and do not want their sexuality to be questioned or judged. In addition, they may be more likely than their heterosexual peers to be single and living alone and less likely to have family support; they may well be estranged from their relatives. This makes formal support more vital.

*Research quoted Don't look back? Improving health and social care service delivery for older LGB users: www.equalityhumanrights.com/sites/default/files/documents/research/dont_look_back_improving_health_and_social_care.pdf

1: The National Dementia Strategy was launched in 2009 www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy See also the Department of Health's Dementia Challenge <http://dementiachallenge.dh.gov.uk/about-the-challenge/>

2: Protected characteristics, as defined by the Equality and Human Rights Commission are age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex and sexual orientation: www.equalityhumanrights.com

3: See the National LGBT Partnership website <http://nationallgbtpartnership.org/>

4: The National Care Forum represents the interest of not-for-profit health and social care providers in the UK: www.nationalcareforum.org.uk

5: Sue Ryder, the hospice and neurological care charity www.sueryder.org

6: The Voluntary Organisations Disability Group is a group of over 80 leading voluntary sector and not-for-profit disability organisations: www.vodg.org.uk

7: DH Strategic Partner Programme: www.gov.uk/government/news/voluntary-groups-lend-a-hand-to-government-to-improve-health-and-wellbeing

8: See endnotes in the Equality and Human Rights Commission report Don't Look Back: www.equalityhumanrights.com/sites/default/files/documents/research/dont_look_back_improving_health_and_social_care.pdf

9: See Age Concern Cymru's research A report of the Older LGBT Network into the specific needs of older lesbian, gay, bisexual and transgender people http://www.openingdoorslondon.org.uk/resources/Age_Concern_Cymru_Older_LGBT_Network_report_2009.pdf

Speakers stressed that people's past experiences of prejudice affect their perception of support. "The generation of older people that we're seeing come into the care sector have lived through massive changes in attitudes ...this is very significant if they develop dementia," said one commentator. Another added: "People in their 80s and 90s really struggled [because of their sexual orientation]...People had electric shock treatment..they were threatened with their families or their bosses finding out".

The roundtable stressed that prejudice still exist, despite a raft of equality rights legislation such as the Equality Act and the Equal Marriage Act (see separate box on The law and LGBT people).

The debate heard an anecdote about staff in one care home who, having supported a burgeoning friendship between two older residents, were horrified to discover they were gay and beginning a relationship. They stopped seating them next to each other and threatened to tell the family of one of the men. Another speaker recalled an older woman she knew who was forced to hide "evidence" of her lesbian life when her home support visited.

Discussion moved onto other challenges faced by those needing support for dementia.

■ Losing inhibitions - or going 'back into the closet'

Reduced inhibition sometimes caused by dementia was a concern, "a fear of losing control over what people say and do", one commentator said. Another described the mental anguish suffered by transgender people with dementia who "have forgotten they transitioned..or forgotten they've not transitioned, or they 'cross-dress' and staff just think they're confused - but that's just what they do to be themselves".

One contributor added: "People 'disappear' in residential care- their identity ceases to exist – not many people are 'out' in care." The debate heard about the worry of being forced "back into the closet" in later life because of the attitudes of care staff.

■ Raising awareness of an ‘invisible population’

Participants described the lack of research into the LGBT population with dementia¹⁰ as another problem. One speaker described the “massive gap” in knowledge. Another added that research exists, but “it’s all disparate...we should be feeding LGBT research into existing dementia research”.

Debate progressed to how awareness raising work must reach all settings - home-based support or residential care. One speaker noted: “We have to make sure we all understand dementia and dignity - what does it look like... The setting isn’t important but it’s about what surrounds people and there are massive differences between providers.”

The roundtable then discussed the fact that LGBT older people are rarely acknowledged by service providers and commissioners. “What we’re talking about here services for people who are likely to be invisible,” said one participant. “The attitude is often ‘we don’t have lesbian and gay people in our care home’ or you’ll hear ‘our manager’s a gay man so we’re probably ok [on equality]”. As work from SCIE (the Social Care Institute for Excellence) shows, “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.”¹¹

The event noted a recent Australian report that stresses how transgender people are invisible within research. The study describes “the experience of stigmatisation and discrimination many transgender and intersex people, indeed all LGBTI people, have encountered during their lives”¹².

Debate then moved towards solutions to the challenges.

10: The issue of “how older LGB people have been overlooked in health and social care legislation, policy, research, guidance and practice, which assume service users are heterosexual” is noted in the Equality and Human Rights Commission report Don’t Look Back: www.equalityhumanrights.com/sites/default/files/documents/research/dont_look_back_improving_health_and_social_care.pdf

11: SCIE Personalisation briefing: Working with lesbian, gay, bisexual and transgender people: <http://www.scie.org.uk/publications/atagance/atagance42.asp>

12: Alzheimer’s Australia report Dementia, transgender and intersex people: do service providers really know what their needs are? https://sa.fightdementia.org.au/sites/default/files/130739_LGBTI%20Discussion%20Paper.2-21.pdf

13: Personalisation is care “starting with the person and their individual circumstances rather than the service”, see SCIE <http://www.scie.org.uk/topic/keyissues/personalisation>

■ Regular support vs. 'rainbow villages'

The event explored the merits of specific care settings for older LGBT people with dementia over "mainstream" support. Discussion included:

- the fact there is "no money sloshing about to develop specific services"
- the idea of "LGBT friendly" dementia support (not LGBT-specific services) being preferable to specific LGBT-only care settings
- people's reluctance to move away from local areas to access suitable specialist care; one contributor noted: "Care is a local service so the idea that people will move from one end of country to another cuts across all those other [local] things that are important in people's lives...an integrated service will be best".

■ Growing more good practice

Participants debated how to improve outcomes based on tackling prejudice. "Fear comes from [care] staff not understanding," one speaker explained of the need to disseminate good practice. The ideas explored included:

- using real life stories in general staff training to mainstream the issue of LGBT people with dementia; one speaker added "It's about lived experience and trying to disseminate it...it's about people and personalisation¹³"
- replicating good practice - for example, the LGBT older tenant group at not-for-profit housing and care provider Anchor has helped influence staff training as well as shape how to better meet the needs of LGBT people.

■ Next steps

Debate participants agreed to progress two pieces of work in early to mid 2015 to positively impact on the wellbeing of older LGBT people:

- a written report that would disseminate good practice through case studies based in a range settings, this publication would help staff, families and people themselves envisage more appropriate care
- the drafting of a practical 'toolkit' for commissioners, raising awareness and supporting them to commission care that supports the specific needs and concerns of older LGBT people.

■ Workforce, regulators and commissioners

Workforce and training are key to developing appropriate support, the roundtable heard. Pressure on regulators and commissioners is vital, and speakers agreed on the following points:

- commissioners are a big part of the solution; one comment was that “they need to incorporate [in contract development] what’s expected of the service”
- “sensitive commissioning would improve support
- regulators must do more: “It comes back to [social care regulator] the Care Quality Commission asking the right questions.” It must “put pressure on commissioning - then it becomes an issue for organisations..Unless someone comes along and says ‘do it’, it doesn’t get done”
- there was some support for a standardised care kite mark for LGBT people with dementia, but speakers noted several platforms already exist to enable people to “rate” the support received.¹⁴

■ Personalisation, dignity and dementia

Ultimately, the debate heard, “it’s about the relationship between the care worker and the person”. At the heart of the issue is “the role of dignity in care”, as one participant summarized. “It’s about people being able to relate to another human being isn’t it?”

Another participant stated that if such an ethos fails to sway care providers, then the pragmatic business argument might (according to Stonewall, gay people make a £40bn contribution every year to the cost of public services¹⁵). One comment was: “Providers need to think ‘this is good for us, good for our organisation - it might bring us new people and colleagues.”

While the modernisation of health and social care is driven by personalisation and concepts of collaboration, choice and control, the roundtable underlined how such drivers are woefully lacking in the care of LGBT people with dementia.

The solutions explored at the debate rest largely on challenging people’s prejudices; as one participant concluded: “What we’re talking about here is societal change.”

■ Further reading:

- Equality and Human Rights Commission report, 2010, Don't look back? Improving health and social care service delivery for older LGB users
- University of Nottingham and University of Manchester, 2014, Care home survey: knowledge, attitudes and practices concerning LGBT residents
- Alzheimer's Australia report, 2014, Dementia, transgender and intersex people: do service providers really know what their needs are?
- Chartered Institute of Housing practice brief, 2011, Delivering housing services to lesbian, gay, bisexual and transgender customers
- Stonewall report, 2011, Lesbian, gay and bisexual people in later life, and, 2014, LGBT Voices, sharing our past, shaping our future and, 2012, Working with older lesbian, gay and bisexual people, a guide for care and support services
- Age Concern Cymru, 2009, A report of the Older LGBT Network into the specific needs of older lesbian, gay, bisexual and transgender people
- Alzheimer's Society report, 2013, Supporting lesbian, gay and bisexual people with dementia
- Opening Doors London checklist for social care providers Supporting older Lesbian, Gay, Bisexual Transgender people

14: Such platforms include www.carehome.co.uk www.goodcareguide.co.uk and www.yourcarerating.org The Lesbian and Gay Foundation also runs the Pride in Practice quality assurance service for GPs caring for lesbian, gay and bisexual patients www.lgf.org.uk/prideinpractice while the Navajo charter mark has been used by organisations to show they are LGBT-friendly <http://www.navajoonline.org.uk>

15: Stonewall media release including reference to Gay people make a £40bn contribution every year to the cost of our public services: http://www.stonewall.org.uk/media/current_releases/9234.asp

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.

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

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.

- Information drafted based on the Chartered Institute of Housing brief Delivering Housing services to LGBT customers and information from the Equality and Human Rights Commission.

