

Forget Us Not

LGBTQ People Rights and Dementia



Community Discussion Summary

In late November 2018, LGBT Health and Wellbeing facilitated a community discussion focused on exploring the needs and rights of LGBTQ people affected by dementia.



Background

COMMUNITY DISCUSSIONS

Housing and the LGBTQ+ Community
Tuesday 20th November | 6.45-8.45pm
Centre for Contemporary Arts (CCA), 350 Sauchiehall Street, Glasgow, G2 3JD
Booking preferred: www.bit.ly/LGBTQHousing
Our home should be our safest space. What problems do LGBTQ+ asylum seekers and refugees face? Are there age specific problems for LGBTQ+ people and housing? What are safety concerns for LGBTQ+ people when looking for housing? Come discuss.

Forget Us Not: LGBTQ People Rights and Dementia
Wednesday 28th November | 6.45-8.45pm
Centre for Contemporary Arts (CCA), 350 Sauchiehall Street, Glasgow, G2 3JD
Booking essential: www.bit.ly/LGBTQDementia
How does dementia affect LGBTQ people and our community? As part of a new national project we are hosting a community discussion exploring the needs, rights and stories of LGBTQ carers and people with dementia. Dementia and carer organisations will join us to share their experience and contribute to discussion.

SQIFF: Pathways to Parenting Film and Discussion
Sunday 9th December | 3-5.30pm
Centre for Contemporary Arts (CCA), 350 Sauchiehall Street, Glasgow, G2 3JD
Join us at SQIFF 2018 for the screening of 'A Deal with the Universe' by Jason Barker, a British documentary about a trans man's pregnancy. We'll then have an informal panel discussion about different pathways to parenthood with a chance for audience members to hear from people who have created families in different ways and to ask them questions about their experiences.

www.lgbthealth.org.uk

With funding from the Life Changes Trust we have established a new project which aims to add to growing learning and practice to ensure that the needs of LGBT people affected by dementia are holistically met.

This event was a partnership between the LGBT Dementia Project and Glasgow Community Programme which aimed to increase our community's knowledge of dementia and generate discussion about how we can better meet the needs of those affected. Volunteers from the Glasgow Community Programme supported us to run the event and ensure it was dementia friendly.

We ensured our event was dementia friendly by consulting guidance from Outside the Box which can be found here: [Making your Group Dementia Friendly Handy Tips for Staff](#)

Partners from Alzheimer's Scotland and TIDE (Together in Dementia Everyday) provided short informal inputs on their experience working in dementia services and supporting LGBTQ people. They then participated in our question and answer panel and open discussion.

Contributions from the Panel

Megan Johnson (Project Co-ordinator, National LGBT Dementia Project)

Key Points

- Megan shared common queries the project has received so far. These have included enquiries about supporting trans people with dementia (in particular concerns about regression of memory/identity after transition)
- There have also been a number of enquiries focussed on the relationship between HIV and dementia. ([HIV associated Dementia](#))
- Explored general themes of stigma and lack of knowledge of LGBTQ experiences within the care sector- many services have no record of working with LGBTQ people, which we know is very unlikely.
- Further queries, that were less expected to emerge, are around how to come out to a person with dementia as an LGBTQ person.
- LGBTQ people are more likely to rely on formal care, or have carers come into their homes. LGBTQ people have concerns about experiencing discrimination from staff, but also peers. Taking a person-centred approach means considering this.



David Ward (LGBTQ Inclusion Lead, TIDE Scotland)

Key Points

- Carers often feel unseen and under supported. For LGBTQ carers this is further exacerbated.
- It is essential to good practice to be visibly inclusive and take small steps to foster a safe environment.
- David gave a good practice example of a care home where the staff started wearing rainbow lanyards, after which 21 residents openly identified as LGBTQ to the staff.
- David also cited the example of gender neutral and dementia friendly toilets (which were situated in the venue) as a step made by dementia rights and LGBTQ organisations together to create spaces inclusive for LGBTQ people with dementia.

Jennifer Hall (Helpline Manager, Alzheimer's Scotland)

Key Points

- Jennifer talked about her experience supporting people with dementia. She highlighted that the LGBTQ community is still often invisible within dementia care.
- The sexuality of LGBTQ people affected by dementia is often disregarded, often treated as a secondary need or identity. Services are not currently asking people with dementia the right questions to uncover these things.
- Lots of LGBTQ people have spoken about their anxiety and distress about coming out to services. One of the ways that we can demonstrate that our services are inclusive environments is to start having a more active voice on LGBTQ issues.
- For example, Alzheimer's Scotland participated in the first Highlands and Islands Pride event despite local resistance to the event.
- Creating more inclusive workspaces and practices will also encourage more LGBTQ people to join the sector workforce. Small things such as expanding binary gender options on job applications can help achieve this.

Question and answer

After the panellists provided their inputs members of the group were invited to ask questions and make comments on what they had heard.

How can services be more inclusive of LGBTQ people?

David - Remember that language matters. Ask open questions. Let people define their identity and needs for themselves.

Megan – LGBTQ people are not trying to hide themselves from services but often feel uncomfortable coming out. Services should put themselves out to LGBTQ people more by using inclusive language. Try not to worry about the people that this language might confuse, they are not the ones you are trying to reach.



How do we support LGBTQ people with dementia to have safe sex?

Jennifer – People with dementia are definitely having sex, a lot of the concerns when people are diagnosed are around capacity to consent.

Megan – Often the presumption is that people do not have the capacity, rather than allowing people to be agents in deciding their own capacity. Much of the narrative around experiences of dementia is extremely heteronormative, which leaves out LGBTQ people's specific issues and experiences.

Attendee comment – Lots of the desexualised language that is used to talk about older people and people with dementia mirrors the language used to erase queer women. For example, use of words such as 'sensual' rather than 'sexual'. It is deliberately erasing, and strips both queer people and older people of agency.

How do we prevent this erasure of LGBTQ sexuality?

David – It is considered taboo and we need to fight against it to create truly inclusive services.

Jennifer – How can we support people through the last intimate moments of their lives, if we can't even talk about it? What is the stigma of two people who love each other having sex?

Megan – heteronormative assumptions are often made about people's sexual identities. For example, the assumption that people with dementia are only having sex with one partner when this might not be the case.



Group Discussion: key points and recommendations

Attendees then took part in small group discussions. The discussions were focused on 4 questions:

- 1) What might be different for LGBTQ carers?
- 2) How does dementia affect LGBTQ people differently?
- 3) What can we do as a community for LGBT people affected by dementia?
- 4) What does a human rights based approach look like for LGBTQ people affected by dementia?
- 5) Attendees recorded the thoughts and discussion points that had emerged in their groups, which have been collated for this summary.

The key topics which were discussed in relation to each question were:

What might be different for LGBTQ carers?

- Potentially having to care for family members who have never validated or respected their identity
- Not being out to the person you are providing care for- having to conceal relationships or expression of gender and the psychological impact this may have.
- Not having their identities honoured in care plans

How does dementia affect LGBTQ people differently?

- If you are in formal care this can mean being forced back into a very gendered/heteronormative space. This can mean a total change to lifestyle and erase peoples boundaries
- Assumptions are made that a person could not both have a disability and be LGBTQIA.
- Presumption of the nuclear family unit: people with dementia are presumed to have children or partners to provide care.
- The impact may depend on the stage of the dementia.
- Dementia can make LGBT people lonelier, more excluded.
- They experience multiple stigmas because of the diagnosis of dementia and their sexuality.
- LGBTQ people may feel excluded from dementia groups
- You may feel less able to advocate for yourself and your rights

What can we do as a community for LGBT people affected by dementia?

- Make LGBTQ community events dementia friend.
- Raise awareness of the issue in our workplaces, communities and families.
- Don't contribute to denying other LGBTQ people sexual expression because of their age or diagnosis.
- Alter our behaviour to accommodate people with dementia. For example, speaking slowly and repeating things.
- Advocate for them
- Acknowledge and celebrate the existence of LGBTQ people affected by dementia in big and little ways

What does a human rights based approach look like for LGBTQ people affected by dementia?

- To have a right to continue living well and stay part of your chosen community.
- To have a right to express their identity. For example, in choices of clothing or make up.
- Using inclusive language can be the difference between someone being out or not being out.
- More crossover training for health professionals to ensure person centred approach




“I got a lot of info that will be helpful to me... tonight was so well organized and very positive... moving forward there will be changes that will improve the lives of LGBT people with Dementia that was clear after listening to the folk who represented the organisations there tonight a very worthwhile event, and something EVERYONE should be thinking about the lives of LGBTQ People, Rights... And Dementia.”



How to Get in Touch


If you are affected by dementia and would like to find out more about getting involved in the project you can contact Megan on:

 megan@lgbthealth.org.uk

 0141 271 2330 or 07949 472 829

To find out more about how we can support you to support LGBT people you are working with and to keep up with further briefings contact Megan on

 megan@lgbthealth.org.uk

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We'd love to hear from you if you have an example to share of good practice in supporting LGBT people affected by dementia.