

On one influential estimate, there are 56,000 lesbian and gay people living with dementia in the UK (McParland & Camic 2016). When people with other LGBT sexual or gender identities are also taken into account, along with those who care for them, there are significant implications for professionals. Yet LGBT people's needs are often overlooked in dementia care as in wider society, as we will argue here before setting out our approach to the issue.

There was no specific reference to LGBT issues in the National Dementia Strategy (Department of Health 2009) and consequently there is little training that focuses on the challenges faced by people with dementia in the LGBT community. Although health care providers have legal and ethical obligations to meet the unique needs of each person, the Social Care Institute for Excellence (2011) found that LGBT people's specific needs were rarely considered in the planning and delivery of services.

Needs overlooked

But the problems have to do with the context as much as content of services. The Equality and Human Rights Commission (EHRC 2009), for example, argued that the health and social care needs of older lesbian, gay and bisexual people were overlooked in legislation, policy, research and practice, which all tended to assume that service users were heterosexual.

Even when the law has been updated, it has not always translated into changes in attitudes and behaviour. For example, more than half of LGBT young people are bullied at school and one in six has been a victim of a hate crime. Two in five trans people have been physically intimidated

■ Sarah Monks is lead dementia nurse specialist at Salford Royal Foundation Trust and Angie Shaw is lead dementia nurse at University Hospital of South Manchester Foundation Trust.

LGBT and dementia: what do we know?

LGBT people's needs are often overlooked in dementia care. **Sarah Monks** and **Angie Shaw** explain the problem and one way to solve it

and many LGBT people are afraid to show affection in public (Stonewall 2017).

There is no reason to doubt that LGBT people with dementia face the same attitudes and therefore double discrimination, both on account of their dementia and on account of their sexual or gender identity. Experiences of stigma, discrimination and exclusion can impact on the lives, experiences and personhood of LGBT people and form a significant part of their personal biographies. Since post-diagnostic support emphasises the importance of biography and life story, such experiences can have major consequences for LGBT people who develop dementia, partly in terms of what they have chosen to say – or not say – about their past lives.

As lesbian, gay and bisexual people are more than 50% more likely to rely on social care, GPs and paid carers for support than heterosexual people (Stonewall 2011), it is critical that services are inclusive and non-discriminatory. Yet around half of lesbian and gay people aged 60 or over would not feel comfortable to disclose their sexual orientation to health care providers (EHRC 2009; Stonewall 2011).

Six out of 10 LGBT people are not confident that social care and support services will understand or meet their needs (Stonewall 2011), while 61% of trans people feel they have to educate health professionals and worry about who would do this if they lacked capacity to do so themselves. These concerns are accentuated by the fact that LGBT people are more likely to be estranged from their

family of origin, more likely to live alone and less likely to have children than their non-LGBT peers (Westwood & Price 2016).

Family and informal carers provide the majority of care to people with dementia, but in the case of LGBT people this is more likely to be from families of choice than families of origin and these families are more likely to be single-generational. Such families of choice and other social networks may lack the legal certainties of "next of kin" biological or marriage relationships.

This can lead to problems with disclosure and discussion of health information and best interests as health and social care systems and staff tend to record information in ways which may not capture the reality of LGBT relationships. This is significant if best interests are discussed and decisions made on behalf of LGBT people living with dementia. Some biological families may be unwilling to acknowledge or honour the sexual or gender identity of the person.

In response to the evident gaps in services, we facilitated the first event of its kind to capture conversations and ideas for best practice developed by people with personal and professional experiences of these unique challenges. It resulted from a collaboration between our hospital dementia team, the LGBT staff network here, Alzheimer's Society and the LGBT Foundation, and among the main contributors was expert by experience Patrick Etnenes, who gave a presentation based on his personal journey.

How the event worked

Alzheimer's Society and the LGBT Foundation advised on how best to facilitate the event. To enable safe and honest sharing of ideas, we ensured supportive and inclusive facilitation which acknowledged the diverse background and experiences of the attendees.

We decided to put on a 2.5 hour evening workshop which took the following form: setting the scene, a lived experience talk, an activity based on the importance of identity and support networks, and an exercise based on developing best practice in hospitals, hospices, nursing homes, GP surgeries and memory services.

Our concluding discussion focused on whether to establish a LGBT and dementia network, which might be able to improve practice and people's experiences of services. Fifty spaces were made available in the workshop, which was advertised via partners, social media and local community groups. Event room and refreshments were funded by the hospital and our partners gave their advice free of charge.

In the end more than 30 people attended, including people living with dementia, carers and health care professionals. Some identified as LGBT. Twelve people were unable to attend and asked to be updated with future developments and opportunities to engage.

Feedback

The workshop was well received and comments made afterwards supported further work on LGBT dementia care. Here is a sample of the comments:

I had been able to explore the complexities faced by LGBT people living with dementia.

Effectively raised awareness and prompted reflection on how we respond individually and collectively.

Opened my eyes to the barriers faced and how we as an organisation can change our approach.

The workshop was valuable because it has led to greater understanding. Our thoughts and views can shape the future.

Raised awareness around gender issues which need to be considered.

Implications for practice

Given the distinct absence of advice, guidance and training at national level, there is a responsibility locally to identify and shape non-discriminatory and person-centred services. Workshop attendees agreed that health and social care organisations should demonstrate their commitment to equity for LGBT people in order to provide a “safe space”, improving access and engagement.

They wanted more education and training for staff and better governance for providers, particularly to recognise LGBT groups by (for example) modifying next of kin recording on admission documents which are usually geared towards biological families.

Also highlighted were easier access to GP services, restricted by frequently poor management of sensitive information by reception staff; measures to improve engagement with memory services and counter the fear of stigma arising from the lack of LGBT-specific support; and better access to end of life care, now problematic because the status of families of choice and informal support networks is legally uncertain and unfamiliar to services.

Attendees at the workshop gave direction and guidance aimed at removing barriers and promoting inclusivity. This included:

- improved visibility of LGBT people living with dementia in

educational and promotional literature, including visual representations of non-heterosexual families as a matter of course

- specific education and training in awareness of gender and sexuality issues

- improvements in monitoring to inform services of local need and to enable the capture of information in a sensitive and timely manner

- governance processes adapted to recognise and include informal support networks and families of choice, changing the language of “next of kin” with its heteronormative implications to more inclusive categories such as “significant other” or “partner in care”
- specific training and guidance on the physical health needs of people who have had genital reconstruction and other surgeries as well as the implications of long-term hormone replacement.

Finally, a scoping exercise for the development of a LGBT and Dementia Network Alliance in the region revealed significant interest. Further meetings are planned to formalise the structure and purpose of the alliance. ■

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PERSPECTIVES



By Rachael Litherland

Punished for living well

■ Rachael Litherland is director at Innovations in Dementia

There have been several news stories about people who say they have lost money in the transfer from disability living allowance to the new personal independence payments (PIP). A high profile example is Alzheimer's Society ambassador Joy Watson, who hit the headlines shortly before the United Nations issued its damning report* criticising the UK's record on disability benefits like PIP.

Joy is reported as saying “I just feel I have been punished for trying to live well with dementia” and needless to say the government's treatment of people with dementia, both with regard to PIP and to back to work assessments, is also exercising many members of the DEEP network at the moment.

The DEEP network is currently collecting additional experiences from other people with dementia. Many have been raising their concerns with their local MPs and Nigel, an active DEEP member, is producing guidance about the actions that people could take locally to get these issues on to political agendas.

This is an open letter to politicians from the Forget Me Nots, an involvement group of people with dementia from East Kent, reflecting their perspective on this very current political issue:

“The current assessments in place are **unfit for purpose** and **highly distressing** for the individuals undergoing them.

“In October 2016, [government minister] Damian Green stated that Employment Support Allowance would continue automatically for those with lifelong and progressive conditions:

We want the welfare state to work for everyone, just as we want the economy to work for everyone, and there are a group of people for whom constant reassessment is pointless and which does increase their stress and anxiety levels.

“From start to finish, the assessment process for both the Back to Work and PIP are inaccessible for individuals struggling with the cognitive challenges of filling out lengthy forms and expressing the difficulties they face in the correct ‘language’ for the professionals to understand. Members of this group have found the assessors interviewing them to be unqualified and with no basic knowledge of either the condition or how it affects individuals on a day to day basis. On several occasions, members of the group have witnessed the results of their ‘diagnostic tests’ in the assessment to be inaccurately recorded by the assessors.

“The consequences of an inadequate assessment can be devastating. Being unable to express their disabilities in the manner recognised by the current PIP system can result in people not only losing their financial support, but also has a knock-on effect to many other aspects of their daily life, e.g. loss of their access to the community after having their blue badges and form of transport removed. Being deemed ‘fit to work’ by an assessment that seemingly has no understanding of the condition could potentially result in serious risk to the individual and others.

“We need your backing because we feel abandoned.”

*For more coverage of the report from the UN Committee on the Rights of Persons with Disabilities – and East Kent Forget Me Nots member Keith Oliver's role in giving evidence to the committee – turn to pages 30-35.