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.

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 fee 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 heterosexual 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.

References


Social Care Institute for Excellence (2011) Working with lesbian, gay, bisexual and transgender people (At a glance briefing 42). London: SCIE.


PERSPECTIVES

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 Not member Keith Oliver’s role in giving evidence to the committee – turn to pages 30-35.