



Maja Janicova

Opinion

Maja Janicova writes about the need to improve care for people with dementia in under-represented groups

Stepping up support



ILLUSTRATION Sara Gelfgren

I recently had the privilege to work with Mike Parish and Tom Hughes—a wonderful couple—and it is with their permission and encouragement that I write this. Mike has supported his husband Tom through dementia and increasing communication difficulties, and the couple are publicly campaigning to improve services for people with dementia and their carers within the LGBT+ community. I am inspired by the energy and determination they have shown.

As a couple of more than 40 years, Mike and Tom have had to

overcome a number of challenges in the past. When Tom was diagnosed with a rare form of dementia called HAND (HIV-associated neurocognitive disorder) a new set of challenges presented themselves.

Dementia is no longer considered an 'old people's disease', but a disease of the brain—one that takes away skills that patients once had, in the same way as a brain tumour, a stroke or motor neurone disease might. Despite this, pathways to provide support to people with dementia are not clearly defined, or are in the process of being

developed, with speech and language therapy often not indicated due to the reduced ability of patients to retain information or learn new skills.

This is perhaps understandable in the light of squeezed budgets, as there is currently little evidence for the efficacy of these therapies. With few exceptions, most NHS patients receive a limited number of sessions with an SLT before being sent home with basic advice and minimal support as their condition deteriorates.

“Communication difficulties vary across different types of dementias”

For Mike, this wasn't enough. Seeing his partner's skills diminishing, he started to ask questions and reach out to anybody he could to find the right support. Both Mike and Tom now contribute to numerous local and national projects, webinars, and talks to raise awareness about the need to improve care for people with dementia from under-represented groups, such as the LGBT+ community.

I have observed that charities and various organisations are increasingly involved in providing various types of support, including communication support, for people with different types of dementia. But are we, as a profession, missing out on something huge here?

Communication difficulties vary vastly across different types of dementias and at different stages of the disease. Is it not the role of SLTs to help shape policies and contribute to research to help provide more understanding into different types of dementia and to better support carers?

Mike has become a huge advocate of bringing people

together who are in a similar situation to Tom's and has set up the first ever platform where these issues can be raised. He would like to reach out via this platform (forbrian.co) to encourage greater support for service users from the LGBT+ community, in order to empower them on their difficult journeys. Mike is also happy to respond to any questions SLTs might have for him and can be reached at mikeparish@forbrian.co

Other useful links for SLTs, service users and carers:

■ My Life Films is a company who that will make a free documentary for those with dementia, very much like a communication passport: mylifefilms.org

■ The Dementia Action Alliance Seldom Heard Groups campaign to improve outcomes for groups that include the LGBT+ community: bit.ly/2qljX0D

■ Dr Jane Youell is a chartered psychologist and dementia specialist who is researching issues around intimacy in dementia. She would like to hear from interested readers. Email her at JYouellConsultancy@gmail.com or visit her website: janeyouell.com

■ LGBT+ carers-only group: www.albanytrust.org/services

■ The Wellcome Trust has started a project on dementia and the arts: bit.ly/2VfFI6C and bit.ly/2EdtWtT

■ Opening Doors London (a charity providing support services for older LGBT+ people) Rainbow Memory Café: bit.ly/2BSmnRY

■ The Alzheimer's Society also has a number of helpful groups, including a young dementia onset group and a carers' group. www.alzheimers.org.uk/ ■

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