

# LGBTQI+ People Living with Dementia

## Context of increased risk

A 2019 study involving 70,000 people in 155 countries looked at LGBTQI+ peoples experiences in Dementia care. According Victor Madrigal-Borloz, (United Nations Independent Expert, Harvard Law School Human Rights Program) LGBTQI+ people did not perceive housing and support services for older persons as safe or welcoming. Sometimes family and care staff refused to affirm the gender identity of older trans persons and forced them to live in denial of their orientation. Even in environments where legal protection was solid, research still identified loss of an LGBT identity, due to the lack of cultural competence of health care services. “Research and data on the lived realities of older LGBT persons living with Alzheimer’s disease is simply non-existent” (World Alzheimer Report 2019, Attitudes to dementia).

<https://www.alzint.org/u/WorldAlzheimerReport2019.pdf>

In July 2021 Alzheimer’s Association International Conference (AAIC) in Colorado presented data from a large annual survey – a study of 231,414 individuals, which included 955 trans or nonbinary adults. Data suggested they were more likely to experience worsening memory or thinking. They reported that **1 in 6 trans** adults reported experiencing problems with cognition, compared to **1 in 10 cisgender** adults.

[https://aaic.alz.org/releases\\_2021/transgender-adults-cognition.asp](https://aaic.alz.org/releases_2021/transgender-adults-cognition.asp)

<https://www.dementiaresearcher.nihr.ac.uk/transgender-adults-more-likely-to-experience-subjective-cognitive-decline-depression/>

In 2022 Smith et al published their findings in a scoping review of LGBTQI+ peoples experiences of dementia care. The report was published by Cambridge University Press. They said, “The significance of life-long experiences of personal, social and systemic discrimination among LGBT older people with dementia, should not be underestimated.

<https://www.cambridge.org/core/journals/ageing-and-society/article/investigating-the-lived-experience-of-lgbt-people-with-dementia-and-their-care-partners-a-scoping-review/197F05C0840110D1CB71E84A38E318EB>

In 2023 Saunders et al published their findings of study involving 850,000 survey responses by Department of Public Health and Primary Care, University of Cambridge. Including were over 6,300 responses where individuals identified as either trans or non-binary. (BMJ, 2023) According to Catherine Saunders “After adjustment for age, ethnicity and deprivation, trans and non-binary adults...were around **three times** as likely to be living with dementia...” Alzheimer’s disease or other causes of dementia **96 (1.9 %)** trans and nonbinary respondents, compared to **5471 (0.7 %)** other survey respondents.

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9895920/>

## Conclusion –

The studies used significant enough numbers to illustrate there is cause for concern at the increased risk of dementia, intersecting with the lack of understanding, or good care provision.

### **Health risks and hidden harm.**

The increased risk of dementia brings other potential hidden harms. The risk of dementia related hidden harm is aggravated due to the fact that care givers have no right to know the person they are caring for is LGBTQI+. The dichotomy is that Care Act asserts that the needs of those who are cared for should not be overlooked, downplayed or ignored.

People may forget to take medications. For example, a person may forget to take HIV medications and dormant cells will reactivate, or the body will build up a resistance. Trans people may forget health screening needs. Trans men may need smear tests, hysterectomy or breast cancer screening. Trans women may need prostate checks, they may forget to take hormones, and, if they have had lower surgery in certain circumstances forget to dilate or douche. Both are lifelong requirements, for some trans women, and trans men if they have penile construction but elect to keep their vagina.

The risks if a person does not douche, really have not been considered. There is little research, and services that have been approached to date demonstrate they have no understanding, nor have any provision for douching and dilation support. Services include Dementia Nurses, Integrated Care Systems, Nuffield Health hospital (who undertake lower surgeries on behalf of Gender Identity Clinics).

When approached, no service was able to indicate what harm could occur if a trans person did not douche. Douching is necessary because the neo-vagina of a trans woman has less lubrication and self-cleaning oven effect than a cisgender woman. Nor does it have natural acidic pH which keeps vaginal flora in check. To compensate douching is needed to flush out skin cells, dried up lube and overgrowth of bacteria that like to hang out in basic pH vagina.

<https://www.mozaiccare.net/vaginoplasty-faqs>

Because no organisation has been able to indicate what risks a trans person would face if they did not douche it necessitated some self-study. According to Van de Sluis et al, a trans woman's neo-vagina is a microbial and fungal niche. The Sepsis Alliance also asserts one in five people including trans women who have had vaginoplasty have at least one Urinary Tract Infection (UTI) in their lifetime. Some more than once. This is because a shorter urethra means the bacteria have less distance to travel into the urinary tract. Trans men who have had phalloplasty can also develop UTIs (Not as common because the bacteria have farther to travel). A bladder infection, may result in sepsis, even while taking antibiotics. And, sepsis could be a hidden harm if a caregiver does not understand the risks facing a trans person.

The study of Van de Sluis et al suggests the following health risks can occur in neo-vagina.

**Staphylococcus epidermidis** - pain, purulence (pus) around the site of the infection, and sepsis.

**Streptococcus anginosus** - found to cause infections within the abdominal cavity including liver abscesses.

**Corynebacterium diphtheriae** - a pathogenic bacterium that causes diphtheria.

**Mobiluncus curtisii**- infection and sepsis.

**Bacterial overgrowth** - sometimes described as dysbiosis, may cause neovaginal discharge and discomfort.

**Enterococcus faecalis** – UTI's

Van de Sluis et al (2020). Neovaginal discharge in transgender women after vaginoplasty: A diagnostic and treatment algorithm. International journal of transgender health, 21(4), 367–372. <https://doi.org/10.1080/26895269.2020.1725710>

<https://www.sepsis.org/sepsisand/urinary-tract-infections/>

## Conclusion

Despite the findings of Victor Madrigal-Borloz and world Alzheimer's Report 2019, and the two significant studies indicating trans people are at heightened risk of living with dementia, care giving services are simply not prepared to support the LGBTQI+ community.

Increased understanding is required in order to avoid health inequity, and the hidden harms that may arise when a person loses the ability to self-support or advocate. Harms that include sepsis seems to be evident. But no studies have been found exploring what may happen if a trans person does not douche or dilate. The concern is that those who have a responsibility to explore such issues are deflecting the need on to others.