

Dementia within the LGBT+ community



It is estimated that up to 10% of the population identifies as lesbian, gay, bisexual, transgender, queer/questioning or another sexual orientation/identity that falls under the LGBT+ umbrella.

An estimated 68,000 LGBT+ people in the UK are thought to be living with dementia. However, this figure is likely to be much higher, as many members of the LGBT+ community, particularly older people, have had negative experiences of health and social care in the past, and so are reluctant to seek support and a formal diagnosis.

Stigma, discrimination and fear

If you are a member of the LGBT+ community who is living with dementia, or supporting an LGBT+ person with dementia, it is likely that you will share many of the experiences and concerns of people who do not identify as LGBT+. However, you may also face different challenges resulting from a history of stigma, oppression and trauma that still touches your life today.

Many older LGBT+ adults have lived a significant part of their lives in a time where prejudice, discrimination and violence against the community were rife. For example, many older people who identify as LGBT+ grew up during the period when homosexuality was considered a mental illness and was an illegal practice.

While attitudes towards the LGBT+ community are improving, many younger LGBT+ people with dementia have also had negative and distressing experiences.

As a result, you might be wary of interacting with health and social care services in case you experience misunderstanding, judgement or discrimination directed at yourself or the person you care for, leading to a delay in getting a diagnosis of dementia and accessing follow-up medical care and support from Social Services. This



could have a negative impact on the overall health, wellbeing and independence of yourself or the person you care for.

If you are an LGBT+ person living with dementia or are supporting someone close to you, you may also be anxious about accessing support groups or social activities due to fear of judgement or negative attitudes from other people. This can further increase social isolation.

However, if you can access inclusive, person-centred care that meets your specific needs, you are likely to feel better equipped and empowered to face the challenges of dementia.

Reducing your risk of dementia

Some things that increase the risk of dementia cannot be changed, like age or ethnicity. But many risk factors can be improved with healthy lifestyle choices. These are known as ‘modifiable risk factors’, and include physical inactivity, smoking, excessive alcohol intake, obesity, high blood pressure (hypertension), diabetes, depression and social isolation.

Several modifiable dementia risk factors are more common in LGBT+ people. This is due to a combination of health, social and lifestyle factors. For example, members of the LGBT+ community are more likely to smoke, drink more than the recommended amount of alcohol and experience depression and social isolation than heterosexual people.

However, positive lifestyle changes can significantly reduce these risks and improve both physical and mental wellbeing.

For more information on causes of dementia and reducing the risk, please see Sources of support on p16.

Looking after brain health

There are many positive things you can do to reduce your risk of developing dementia and, if you do develop the condition, to slow down its progression. These include:

- being physically active
- eating healthily
- not smoking
- not exceeding the recommended amount of alcohol (no more than 14 units per week, with several alcohol-free days)
- keeping socially and mentally active, for example by taking part in hobbies, learning a new skill and joining community groups



Challenges facing people from the LGBT+ community

As a member of the LGBT+ community who is living with dementia, or as a carer of an LGBT+ person, you may experience additional challenges with seeking support from health and social care professionals. These challenges may include:

- judgement and discrimination, including homophobia and transphobia
- a lack of specialised support services and resources tailored to your specific needs
- needing to make challenging decisions about whether to disclose information about sexual orientation or gender identity to health and social care professionals and others

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- receiving unequal treatment on the grounds of sexuality or gender identity, eg being denied access to single-sex spaces
- inappropriate curiosity around your sexuality, gender and preferences
- receiving ‘heteronormative’ health and social care – this refers to an inbuilt lack of inclusion that assumes heterosexuality is the default sexual orientation
- difficulties when engaging with activities like reminiscence therapy or life story work, which could trigger past trauma
- lack of recognition of ‘families of choice’ (people who are not related to the person with dementia, but who they consider to be family), which can lead to them being excluded from health and care decisions
- changes in behaviours and symptoms such as disinhibition, which may put a strain on relationships with family and friends – for example, a person with dementia may disclose information about someone’s gender identity to others without their consent

Getting a diagnosis of dementia

Research indicates that LGBT+ people may be less likely to seek a diagnosis of dementia. This is often due to fear of discrimination or past negative experiences with healthcare. Older LGBT+ adults are also more likely to live alone. This may mean they have fewer people around to notice changes in memory and thinking or encourage them to get a memory assessment.

If you notice changes in memory or thinking in yourself or someone close to you, it is important to see a GP. Initiating the process of getting a memory assessment can feel daunting, especially if you have had negative experiences of healthcare in the past.



However, putting off seeking medical advice and getting a memory assessment may mean opportunities for early support, treatment and care are missed.

Getting a prompt diagnosis means you can:

- access the right care and treatment sooner; this may include medication for some forms of dementia to slow progression and make the symptoms more manageable
- access appropriate support services and benefits
- maintain independence for longer
- plan for the future

For more information on getting a diagnosis of dementia, please see Sources of support on p17.

How dementia symptoms may impact a person from the LGBT+ community

Changes in memory and cognitive function (eg thinking, decision-making and problem-solving) are common symptoms of dementia, and these can pose particular challenges for people from the LGBT+ community.

An LGBT+ person may not recall disclosing their sexual orientation or gender identity (often referred to as 'coming out') and therefore may try to conceal this information where they have previously been open about it. For example, they may deny or forget their relationship with a partner. This can impact the person themselves and those closest to them, placing strain on relationships and causing distress and anxiety.

A person who identifies as transgender may no longer recall that they have transitioned, or their memory of this may fluctuate. They may revert to a time prior to their transition, and this could evoke negative experiences and emotions – for example if they previously concealed their gender identity because of a fear of discrimination or judgement from family, friends and professionals.

The person may fluctuate in how they identify, for example in how they dress or the pronouns they use, which could cause additional confusion and tension for them and the people around them, including professional carers. It is important to support and address the person as they identify at that particular time to avoid distress and anxiety.

A person may also be unable to recall that a family member or friend has transitioned, and this may cause challenges within relationships.

The cognitive changes related to dementia may lead to the person reliving experiences of previous trauma or distress. This may be



particularly relevant if they lived through a time where their sexual orientation was illegal or classed as a mental illness, or if they have personally experienced violence or discrimination.

The person might display disinhibited sexual behaviour and language which may increase the risk of judgement and discrimination and make them increasingly vulnerable, particularly in public situations.

The person may also require additional support to remember to take essential medications – this is particularly important if they take regular hormone treatment or HIV medications.

Disclosing information

Disclosing personal information about your own gender identity or sexual orientation or that of the person you are supporting can be difficult. When you are choosing what to disclose, when and to whom, these tips may help.

- Only share information if you are comfortable to do so. Being open about sexual orientation or gender identity can help professionals provide inclusive, tailored care and support that meets your needs – however, there is no obligation to do so
- Consider sharing information that you feel is appropriate to the circumstances. You can always revisit the topic at a later date
- Look for outward signs that the service you are accessing is inclusive and supportive of the LGBT+ community as this may make you feel more comfortable in sharing personal information. There may be posters on the walls, or staff may wear badges that show their support
- Consider creating a life story – a record of important information such as likes and dislikes, personal history, interests and relationships, which can be shared with professionals to help them better understand your needs. Please see Sources of support on p17 for more information and our template

Planning for the future

It is important for the person with dementia to discuss their wishes for the future with family, friends and health and social care professionals and together, make a plan for what they would like to happen – known as an advance care plan. This will help ensure the person's views are documented so that future care is inclusive and respectful of their needs. It covers things like:

- how the person would like to be cared for, and who by
- medical treatments they do and do not want
- where they would prefer to die (eg home, care home, hospital, hospice)



- their funeral wishes and any arrangements that have been made
- details of their Will
- their personal, spiritual and cultural values and how they will be respected
- who they would like to be involved in making decisions if they can no longer do so themselves

An advance care plan can support the person to make decisions about the information they wish to disclose; how they may wish to be identified; and the care they receive. This can guide their care if it becomes harder for them to communicate their plans, preferences and wishes as their condition progresses.

For many reasons, people from the LGBT+ community may lack biological family support and therefore class others who they have

close relationships with as family – often known as their ‘family of choice’. However, health and social care professionals do not always recognise the importance of families of choice. This can lead to significant people being excluded from potentially life-changing conversations and decisions.

In this situation, the person with dementia and those who support them may need to be assertive in making sure the professionals involved understand who is closest to the person and fully include them in the process. Having an advance care plan can help with these conversations. Please see Sources of support on p16 for further information about advance care planning and our template.

It is also important for the person with dementia to make a lasting power of attorney (LPA) to help prevent these potential challenges. This is a legal process appointing one or more trusted people to make decisions on the person’s behalf if they lack the mental capacity to do so themselves. There are two types of LPA: one covering health and welfare decisions, and the other covering decisions about property and financial affairs.

LPA is valid in England and Wales. In Scotland, the equivalent is power of attorney (PoA). In Northern Ireland, it is known as enduring power of attorney (EPA) but this covers only financial affairs and not health and welfare.

Please see Sources of support on p17-18 for more information on all forms of power of attorney, mental capacity and decision-making.

Choosing dementia care for a person from the LGBT+ community

If you are thinking about home care or a move into a care home for an LGBT+ person with dementia, it is important to consider the inclusivity of the care provider. You may see evidence of their



support, such as promotional materials that use LGBT+ images and staff pronouns displayed on their name badges.

You may also like to ask the care provider directly about its equity, diversity and inclusion policy and any training in LGBT+ and dementia awareness that staff have completed. Please see Sources of support on p17 for information on choosing home carers and care homes.

Raising complaints

It is illegal in the UK to discriminate against a person based on sexual orientation and gender reassignment.

If you are concerned about any ill treatment that you have received or witnessed because of your own sexuality or gender identity or that of the person you care for, consider reporting this to the appropriate services. As well as tackling your own complaint or

concern, this could lead to positive changes in how the health or care service supports people.

- All health and care services must have a complaints policy explaining the steps to follow – you can usually find this on their website or ask for a copy
- Contact your local Patient Advice Liaison Service (PALS) if you have concerns about how you have been treated by an NHS professional or team – see Sources of support on p18
- Contact your local Adult Social Care Safeguarding Team to report any concerns about someone's welfare, for example if you suspect harm, abuse or neglect. You can find details through your local council – see Sources of support on p18
- Call 999 if a crime is in progress or someone is in immediate danger

Support from Dementia UK

Dementia UK is committed to supporting members of the LGBT+ community who are affected by dementia. We can support you with issues such as:

- Getting a memory assessment
- Looking after your brain health
- Adjusting to the diagnosis
- Caring for an LGBT+ person who is living with dementia
- Managing symptoms of dementia in relation to the person's sexuality or gender identity
- Difficulties in recognition of families of choice and relationships between carers and services



- Discussing any concerns about health professionals involved in the care of the person with dementia
- Signposting to local support services

If you would like support from a dementia specialist Admiral Nurse, please see Sources of support on p16 for information on contacting our Helpline or booking a phone or video appointment.

Sources of support

If you are caring for someone with dementia or living with the condition yourself, you can register for our free online sessions, 'Dementia: what next?' Hosted by dementia specialist Admiral Nurses, they cover topics like types of dementia, symptoms, financial and legal issues and planning for the future. Sign up at

➤ dementiauk.org/dementia-what-next

To speak to an Admiral Nurse on our free Helpline, call

0800 888 6678 (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email ➤ helpline@dementiauk.org

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit ➤ dementiauk.org/book

Dementia UK resources

Advance care planning

➤ dementiauk.org/advance-care-planning

Advance care plan template

➤ dementiauk.org/advance-care-plan-template

Causes and risk factors of dementia

➤ dementiauk.org/causes-and-risk-factors

Changes in sexual behaviour

➤ dementiauk.org/changes-in-sexual-behaviour

Changing relationships and roles

➤ dementiauk.org/changing-relationships-and-roles

Choosing a care home for a person with young onset dementia

- ➲ dementiauk.org/young-onset-dementia-choosing-a-care-home

Considering a care home for a person with dementia

- ➲ dementiauk.org/considering-a-care-home

Creating a life story

- ➲ dementiauk.org/life-story

Dealing with stigma and discrimination

- ➲ dementiauk.org/dealing-with-stigma

Finding help and support at home

- ➲ dementiauk.org/finding-help-and-support-at-home

Getting a diagnosis of dementia

- ➲ dementiauk.org/how-to-get-a-diagnosis-of-dementia

Lasting power of attorney

- ➲ dementiauk.org/lasting-power-of-attorney

Life story template

- ➲ dementiauk.org/life-story-template

Mental capacity and decision-making

- ➲ dementiauk.org/mental-capacity-and-decision-making

Sex, intimacy and dementia

- ➲ dementiauk.org/sex-intimacy-and-dementia

Other resources**Age UK: LGBT+ support groups for older people**

- ➲ ageuk.org.uk/information-advice/health-wellbeing/relationships-family/lgbt/lgbt-groups

Enduring power of attorney (Northern Ireland)

- ➲ nidirect.gov.uk/articles/managing-your-affairs-and-enduring-power-attorney

Find your local council (to contact the Adult Social Care Safeguarding Team)

➲ gov.uk/find-local-council

LGBT Foundation

➲ lgbt.foundation

➲ lgbt.foundation/pride-in-ageing-living-well-with-dementia

Helpline: 0345 330 3030

LGBTQ Dementia Advisory Group: a network committed to improving the lives of people affected by dementia who identify as LGBTQ+

➲ lgbtqdementia.org

Patient Advice and Liaison Services (PALS)

➲ nhs.uk/service-search/other-health-services/patient-advice-and-liaison-services-pals

Power of attorney (Scotland)

mygov.scot/power-of-attorney

Rainbow call companions: telephone befriending for LGBT+ people over 75

➲ reengage.org.uk/join-a-group/get-a-rainbow-call-companion

Speak out for dementia: online peer support group for LGBT+ people living with dementia

➲ dementiavoices.org.uk/group/lgbtq-group-working-towards-an-identity-and-a-name

Stonewall

➲ stonewall.org.uk

Switchboard Dementia Project

➲ switchboard.org.uk/what-we-do/dementia-project



**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:

0800 888 6678 or helpline@dementiauk.org

Book a virtual appointment:

dementiauk.org/book

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit **dementiauk.org/donate**
- Scan the QR code

Thank you.



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